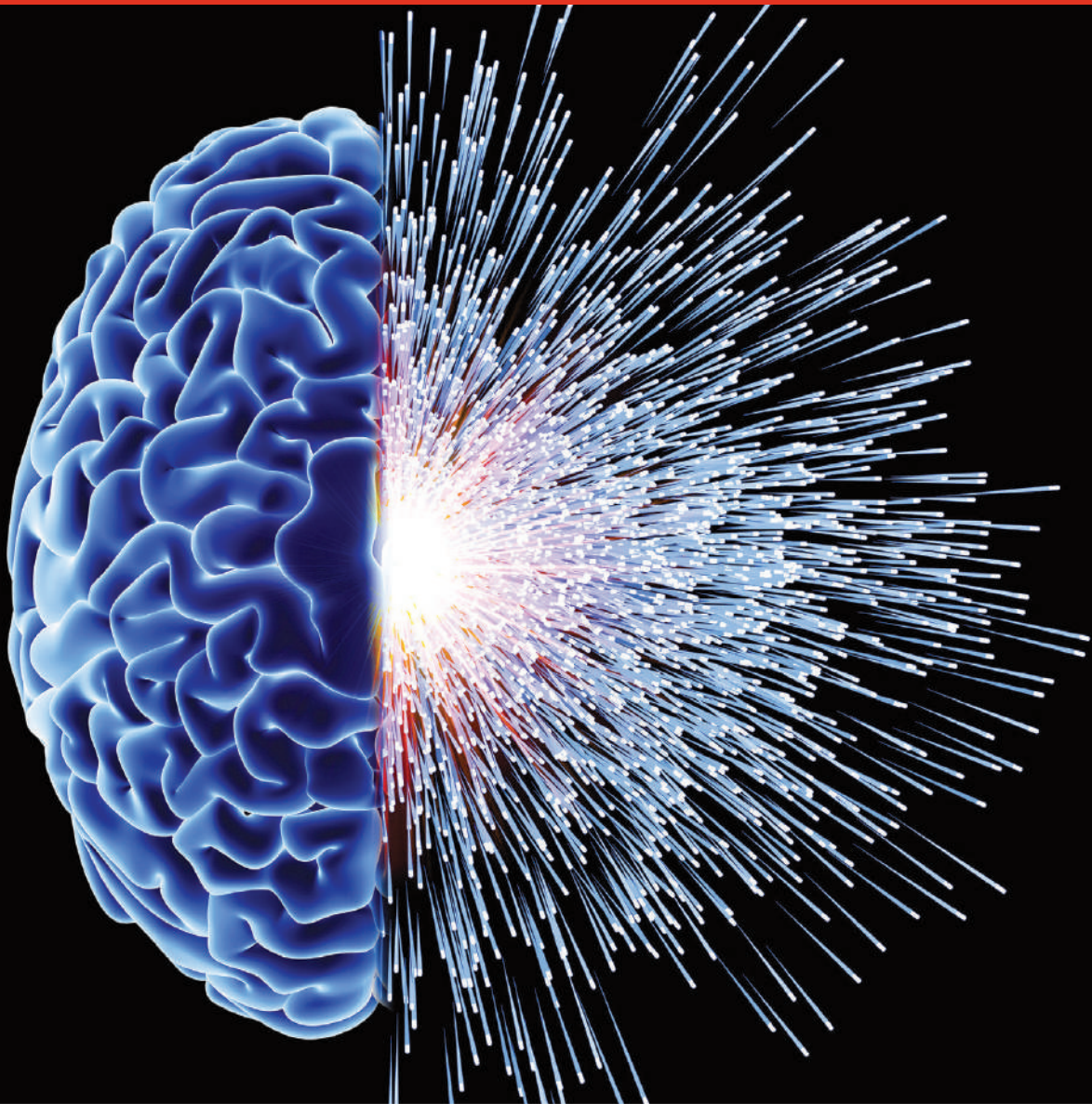


ACNR

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ADVANCES IN CLINICAL NEUROSCIENCE & REHABILITATION



In this issue

Kirstie Anderson – Sleep disorders and the neurologist

Wendy Magee – Why include music therapy in a neurorehabilitation team?

Laura Edwards – Human animal interaction, animal assisted therapy and pet ownership in neurorehabilitation

Gita Ramdharry, Kate Bull, Rebecca Jeffcott, Andrew Frame
– An expert opinion: Rehabilitation options for people with polyneuropathy



YOUR CHOICE FOR AGEING NVAF PATIENTS

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NVAF PATIENTS IN MIND

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- Treatment of deep vein thrombosis (DVT) and pulmonary embolism (PE), and prevention of recurrent DVT and PE in adults

LIXIANA[▼] (edoxaban) 60 mg / 30 mg / 15 mg film-coated tablets prescribing information

Refer to the Lixiana Summary of Product Characteristics (SmPC) prior to prescribing

Presentation: 60 mg (yellow) / 30 mg (pink) / 15 mg (orange) edoxaban (as tosilate) film-coated tablets. **Indications:** Prevention of stroke and systemic embolism in adult patients with non-valvular atrial fibrillation (NVAF) with one or more risk factors, such as congestive heart failure, hypertension, age ≥ 75 years, diabetes mellitus, prior stroke or transient ischaemic attack (TIA). Treatment of deep vein thrombosis (DVT) and pulmonary embolism (PE), and prevention of recurrent DVT and PE in adults. **Posology and method of administration:** NVAF: Recommended dose is 60 mg edoxaban once daily with or without food. Continue therapy long term. VTE: Recommended dose is 60 mg edoxaban once daily with or without food following initial use of parenteral anticoagulant for at least 5 days. Duration of therapy (at least 3 months) should be based on risk profile of the patient. For NVAF and VTE the recommended dose is 30 mg edoxaban once daily in patients with one or more of the following: moderate or severe renal impairment (creatinine clearance (CrCL) 15 - 50 mL/min); low body weight ≤ 60 kg; concomitant use of the P-glycoprotein (P-gp) inhibitors, ciclosporin, dronedarone, erythromycin, or ketoconazole. The 15 mg dose of edoxaban is not indicated as monotherapy, and should only be used during a switch from edoxaban to VKA in certain patients (see SmPC for full details). Edoxaban can be initiated or continued in patients who may require cardioversion. For transoesophageal echocardiogram guided cardioversion in patients not previously treated with anticoagulants, edoxaban should be started at least 2 hours before cardioversion to ensure adequate anticoagulation. Cardioversion should be performed no later than 12 hours after the dose of edoxaban on the day of the procedure. Confirm prior to cardioversion that the patient has taken edoxaban as prescribed. If a dose of edoxaban is missed, the dose should be taken immediately and then continued once daily on the following day. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients. Clinically significant active bleeding. Hepatic disease associated with coagulopathy and clinically relevant bleeding risk. Lesion or condition, if considered to be a significant risk for major bleeding including current or

recent gastrointestinal (GI) ulceration, presence of malignant neoplasms at high risk of bleeding, recent brain or spinal injury, recent brain, spinal or ophthalmic surgery, recent intracranial haemorrhage, known or suspected oesophageal varices, arteriovenous malformations, vascular aneurysms or major intraspinal or intracerebral vascular abnormalities. Uncontrolled severe hypertension. Concomitant treatment with any other anticoagulants e.g. UFH, low molecular weight heparins, heparin derivatives (fondaparinux, etc.), VKA or DOACs except under specific circumstances of switching oral anticoagulant therapy or when UFH is given at doses necessary to maintain an open central venous or arterial catheter. Pregnancy and breast-feeding. **Special warnings and precautions for use: Haemorrhagic risk:** Caution in patients with increased risk of bleeding such as elderly on ASA. Discontinue if severe haemorrhage occurs. The anticoagulant effect of edoxaban cannot be reliably monitored with standard laboratory testing. A specific anticoagulant reversal agent for edoxaban is not available. Haemodialysis does not significantly clear edoxaban. **Renal impairment:** CrCl should be monitored at the initiation of edoxaban and afterwards when clinically indicated. Not recommended in patients with end stage renal disease or on dialysis. **Renal function and N/AF:** A trend towards decreasing efficacy with increasing CrCl was observed for edoxaban compared to well-managed warfarin. Edoxaban should only be used in patients with NVAF and high CrCl after a careful benefit risk evaluation. **Hepatic impairment:** Not recommended in severe hepatic impairment. Caution in mild or moderate hepatic impairment. Caution in patients with elevated liver enzymes (ALT/AST $> 2 \times$ ULN) or total bilirubin $\geq 1.5 \times$ ULN. Perform liver function testing prior to initiation and then periodically monitor for treatment beyond 1 year. **Surgery or other interventions:** discontinue edoxaban as soon as possible and preferably at least 24 hours before the procedure. If procedure cannot be delayed, the increased risk of bleeding should be weighed against urgency of the procedure. Restart edoxaban as soon as haemostasis achieved. **Prosthetic heart valves and moderate to severe mitral stenosis:** Not recommended. **Haemodynamically unstable PE patients or patients who require thrombolysis or pulmonary embolectomy:** Not recommended. **Patients with active cancer:** Not recommended in treatment and/or prevention of VTE. **Patients with a history of thrombosis diagnosed with antiphospholipid syndrome:** DOACs including edoxaban are not recommended. **Drug interactions:** Concomitant use of the

In NVAF patients with high creatinine clearance, there is a trend towards decreasing efficacy with increasing creatinine clearance for edoxaban vs well-managed warfarin, therefore careful evaluation of thromboembolic and bleeding risk is necessary before initiation.

Recommended by NICE and SMC accepted.

References: 1. Giuliano RP *et al.* *N Engl J Med* 2013;369(22):2093-2104; and supplementary appendix. 2. Kato ET *et al.* *J Am Heart Assoc* 2016;5(5). pii: e003432. 3. LIXIANA[®] Summary of Product Characteristics. 4. Ruff CT *et al.* *Lancet* 2015;385(9984):2288-95. 5. Steffel J *et al.* *Eur Heart J* 2018;39:1330-1393.

P-gp inhibitors ciclosporin, dronedarone, erythromycin, or ketoconazole requires edoxaban dose reduction to 30 mg. Edoxaban should be used with caution with concomitant **P-gp inducers** (e.g. rifampicin, phenytoin, carbamazepine, phenobarbital, St John's Wort). Concomitant high dose ASA (325 mg) or chronic NSAIDs is not recommended. Concomitant ASA at doses > 100 mg and < 325 mg should be under medical supervision only. Very limited experience with dual antiplatelet therapy or fibrinolytics. Possibility of increased bleeding risk with concomitant SSRIs or SNRIs. **Adverse reactions:** Common: anaemia, dizziness, headache, epistaxis, abdominal pain, lower GI haemorrhage, upper GI haemorrhage, oral/pharyngeal haemorrhage, nausea, blood bilirubin increased, gamma GT increased, cutaneous soft tissue haemorrhage, rash, pruritus, macroscopic haematuria/urethral haemorrhage, vaginal haemorrhage, puncture site haemorrhage, liver function test abnormal. **Serious uncommon:** thrombocytopenia, hypersensitivity, intracranial haemorrhage (ICH), intraocular haemorrhage, other haemorrhage, haemoptysis, surgical site haemorrhage. **Serious rare:** anaphylactic reaction, allergic oedema, subarachnoid haemorrhage, pericardial haemorrhage, retroperitoneal haemorrhage, intramuscular haemorrhage (no compartment syndrome), intra-articular haemorrhage, subdural haemorrhage, procedural haemorrhage. **Legal classification:** POM. **Package quantities, marketing authorisation (MA) numbers and basic NHS costs:** 60 mg - 28 tablets - EU/1/15/993/018 - £49.00. 30 mg - 28 tablets - EU/1/15/993/005 - £49.00. 15 mg - 10 tablets - EU/1/15/993/001 - £17.50. **MA holder:** Daiichi Sankyo Europe GmbH, Zielstattstrasse 48, 81379 Munich, Germany. **Date of preparation of Prescribing Information:** May 2019 EDX/19/0141

Adverse events should be reported.
Reporting forms and information can be found
at www.mhra.gov.uk/yellowcard.

Adverse events should also be reported to
Daiichi Sankyo UK Pharmacovigilance on 0800 028 5122,
pharmacovigilance@daichi-sankyo.co.uk

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Cover image is from 'Neurology and Religion', Edited by Alasdair Coles and Joanna Collicutt. Image courtesy of Cambridge University Press.



Mike Zandi, Co-Editor.

In this first issue of the 2020s we cover in our review articles the neurological topics of sleep, polyneuropathy therapy, and therapy with music and human-animal-interaction. Dr Kirstie Anderson (Newcastle) presents an approach to taking a sleep-history and uncovering symptoms without forcing 'every symptom a patient gives you into a daytime diagnosis'. Prof Wendy Magee (Philadelphia) rationalises why we should encourage and develop resources for music therapy as part of neurorehabilitation, particularly for motor disorders. There seems to be an effect beyond that of familiarity or enjoyment. Professor Laura Edwards (Nottingham) presents animal assisted therapy and pet ownership for rehabilitation as a resource to improve mood, confidence and motor and language recovery after a range of disorders. Professor Gita Ramdharry (Kingston University, and UCL/National Hospital) with colleagues Kate Bull, Rebecca Jeffcott and Andrew Frame also from the National Hospital, provide an overview of the approach to rehabilitation for individuals with polyneuropathy. A thorough assessment approach with emphasis on exercise with resistance training, selection of orthotics and splinting, education can lead to improved outcomes, and this article provides an excellent educational framework for dealing with a common clinical problem.

In the rest of the journal we have Elohor Ijete, medical student at King's College London, who writes an essay on recognising and challenging stigma in neurological disability, particularly as a barrier to access to effective rehabilitation. This essay contains some useful approaches to challenge stigma, focused on the use of language about disability, and an urgent call to action to those working in media. We have Andrew Larner (Liverpool) argue for the cutting and forgetting of eponyms, particularly for those names known to have been linked to Nazi and other regimes. Long-running contributor JMS Pearce writes on Vladimir Bekhterev, famous for ankylosing spondylitis, but forgotten perhaps for contributions to a range of reflexes (with some eponyms), and his sudden unexplained death and erasure from history within days of examining Stalin. Anne Cooke of the British Neuroscience Association writes on boosting credibility and sustainability in neuroscience research, linked to the launch of their Credibility in Neuroscience manifesto. We have book reviews by Rhys Davies and Ann Donnelly, and seven conference reviews from the past year with a look ahead at conferences in the coming year.

It is 10 years since I started out as a co-Editor of ACNR for the 2010s, so now is the time to bow out and let the journal continue to develop and grow under the guidance of publisher Rachael Hansford, and the current and future editorial team. Rachael's original vision, of a journal that explains the latest advances in research to an audience of mainly clinical practitioners, has held out in my view as a unique and valuable resource, and I encourage readers to contact the journal and submit their writing.

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Fampyra® (fampridine) is first symptomatic treatment in Wales to receive a recommendation for funding as an option for walking impairment in adult patients with all types of MS

Biogen announced on 18th December 2019 that Fampyra® (fampridine) has been recommended for funding by the All Wales Medicines Strategy Group (AWMSG). The recommendation states that 'Fampridine (Fampyra®) is recommended as an option for use within NHS Wales for the improvement of walking in adult patients with multiple sclerosis with walking disability (Expanded Disability Status Scale [EDSS] 4 to 7). This recommendation applies only in circumstances where the approved Wales Patient Access Scheme (WPAS) is utilised or where the list/contract price is equivalent or lower than the WPAS price.'¹

Fampridine is recommended for use in all subtypes of MS, including relapsing remitting MS (RRMS), secondary progressive MS (SPMS), primary progressive MS (PPMS), and progressive relapsing MS (PRMS) that have either very limited or no treatment options, depending on disease severity.²

Wales is the first country in the UK to recommend fampridine

receives funding. The Scottish Medicines Consortia are due to review their funding decision in March 2020.

"Although disease-modifying therapies have been shown to be effective in reducing relapse rates and disease progression in people with relapsing remitting MS, they do not specifically target the symptoms of MS, like problems with walking and general mobility, which can have a significant impact on quality of life," said Dr Simon Beck, Medical Director, Biogen UK & Ireland. "Two out of every three patients with MS will develop a degree of disability and walking impairment,² for which fampridine is licensed, making the AWMSG's recommendation an important step forward for people in Wales who have, until now, been self-funding their own treatment."

References

1. All Wales Medicines Strategy Group Final Appraisal Recommendation – 1919: Fampridine (Fampyra®) 10 mg prolonged-release December 2019.
2. Executive summary of fampridine reimbursement submission.

Ocrelizumab (Ocrevus®) accepted for use in PPMS within NHS Scotland

Ocrelizumab (Ocrevus®) has been accepted for use within NHS Scotland, for the treatment of adult patients with early primary progressive multiple sclerosis (PPMS) in terms of disease duration and level of disability, and with imaging features characteristic of inflammatory activity.

In a randomised, double-blind, phase III study, the risk of disability progression was significantly reduced in patients who received ocrelizumab compared with placebo.

See <https://www.scottishmedicines.org.uk/medicines-advice/ocrelizumab-ocrevus-full-smc2223/>

Richard Erwin, General Manager, Roche UK, said, "Following many years of dedication and hard work by our scientists and the wider scientific community, today's news is a landmark in the treatment of multiple sclerosis. People in Scotland with early, primary progressive multiple sclerosis (PPMS) will now be able to benefit from the first ever licensed treatment on the Scottish NHS. This underlines our commitment to support people in Scotland, across all of the diseases we cover, to live longer and healthier lives. We are proud to have again worked together with key Scottish stakeholders to make this happen."

Symprove – looking at the microbiome beyond the gut

In the last decade, microbiome research has become progressively more extensive, with over 50,000 documents published. Interestingly, "neurodegenerative diseases related to gut microbiota" was one of the dominant fields of research.

Symprove, who manufacture a multi-strain live and active bacteria-based food supplement, are committed to discovering more about the microbiome and its role. Designed to balance gut bacteria in a bid to support general health and wellbeing, Symprove has been in production at a dedicated site in Farnham for nearly twenty years.

An independent clinical trial done by UCL showed that Symprove can reach the gut to survive and multiply (coined as 'arrive, survive, thrive'). Another study looked at gut function and how this is impacted by the use of multi-strain live bacteria products.

We are convinced that this is only the beginning. Emergent research is looking at the impact of Symprove on other components of the microflora and the implications on this for the maintenance of human health. The research into gut health, the microbiome and bacteria-based products is in relative infancy, and we want to be on the path every step of the way.

<http://www.symproveforprofessionals.com/>



New mobile scanner allows CT images of the head directly on the ICU ward

Transporting ICU patients with acute and critical head conditions to the radiology department for CT imaging is staff- and time-intensive. Time that could otherwise be spent on patient care. Siemens have developed SOMATOM On.site, a new mobile head CT scanner that allows scanning of patients directly on the ICU ward.

See more at <https://www.siemens-healthineers.com/computed-tomography/mobile-head-ct/somatom-on-site>

Phase II clinical trial of respiratory drug for treatment of Parkinson's reveals promising results

Results of a Phase II clinical trial evaluating ambroxol as a potential treatment to slow progression of Parkinson's (PD) have shown it can effectively cross the blood-brain barrier and increase levels of glucocerebrosidase (GCase) in the brain cells of people with PD. Between January 2017 and April 2018 a Phase II clinical trial was conducted by Professor Anthony Schapira and his research team at University College, London and the Royal Free Hospital. Results were published in *The Journal of the American Medical Association (JAMA) Neurology* on 13th January, 2020.

Ambroxol is a commonly used medication in Europe, which promotes the clearance of mucus and eases coughing. It is used for the treatment of respiratory diseases, and also has anti-inflammatory properties.

Preclinical experiments suggest that ambroxol may help by bolstering cellular waste disposal systems. In PD, there is evidence to suggest that abnormal proteins are accumulated in cells and are not being disposed of properly. In particular, researchers have found that ambroxol increases levels of a protein called GCase in cells. By increasing levels of GCase, ambroxol allows cells to remove waste more effectively. This would ideally keep cells healthier for longer and therefore slow down the progression of PD.

This study has been funded by CPT in partnership with Van Andel Institute (VAI) and the John Black Charitable Foundation. Further studies will be required to determine if ambroxol is having a disease-modifying impact. CPT, VAI and the John Black Charitable Foundation are now actively exploring the next steps in the clinical testing of ambroxol.

Read more at <https://www.cureparkinsons.org.uk/news/ambroxol-phase-II-results-published>

NICE guidance on cannabis-based medicinal products

The National Council of Health and Care Excellence (NICE) published its first guidance on cannabis-based medicinal products in November 2019. It outlined guidance across 4 key areas: chemotherapy-induced nausea and vomiting, chronic pain, spasticity, and treatment-resistant epilepsy.

NICE have examined the evidence for the use of both cannabidiol (CBD) and delta-9-tetrahydrocannabinol (THC) elements of cannabis to help manage these four areas.

Sativex for spasticity

NICE support the use of Sativex, the cannabis-derived nasal spray to manage spasticity in people with MS. Sativex, which contains both CBD and THC elements of cannabis, is recommended to be offered as a four-week trial to treat those with 'moderate to severe spasticity in MS', if other pharmacological treatments have not been effective, and the drug is being locally commissioned.

Highlighting that the guidance does not recommend cannabis-based treatments for pain relief, the MS Society also note the challenge of leaving Sativex to local provision - this is reliant on local bodies having the resources required, and could contribute to the challenge of unwanted variance in MS service provision in the UK.

Chronic pain

Chronic pain is a frequent component of a number of neurological conditions. However, the guidance does not recommend the use of cannabis-related medicines to help manage chronic pain, listing the various medicines not to be offered, and noting that CBD alone may only be offered 'as part of a clinical trial'.

Severe treatment-resistant epilepsy

NICE has made research recommendations on the use of cannabis-based medicinal products for severe treatment-resistant epilepsy and has recommended Epidiolex, a purified cannabidiol (CBD) oral solution, for use in the NHS for two rare and severe epilepsies, Lennox-Gastaut syndrome and Dravet syndrome.

<https://www.nice.org.uk/guidance/ng144>

Fremanezumab: Chronic and episodic migraine medication approved for use within NHS Scotland

On 13th January, 2020 the Scottish Medicines Consortium (SMC) announced that Fremanezumab (Ajovy) has been accepted for restricted use within NHS Scotland, for the treatment of adults with chronic and episodic migraine who have had prior failure on three or more migraine preventive treatments.

Ajovy, from Teva Pharmaceuticals, is the first dedicated migraine preventive medication that will be available to treat both chronic and episodic migraine.

It is a new class of drug which works by inhibiting a small protein found in nerve cells called calcitonin gene-related peptide (CGRP), which is believed to be involved in causing the pain in migraine attacks.

Scotland is the only nation in the UK where CGRP inhibitors have been approved to treat migraine on the NHS.

EU approval of Mayzent® (siponimod) for adult patients with secondary progressive multiple sclerosis (SPMS) with active disease

On 20th January 2020, Novartis announced that Mayzent® (siponimod) has been approved as the first and only oral treatment specifically indicated for patients with secondary progressive multiple sclerosis (SPMS) with active disease in Europe.¹

Mayzent addresses an unmet need for SPMS patients with active disease who, until now, did not have an oral treatment that has been shown to be effective in delaying progression in this patient population.

Approval is based on the Phase III EXPAND trial, the largest randomised clinical study in a broad range of SPMS patients, showing Mayzent significantly reduced the risk of disease progression, including physical disability and cognitive decline.^{2,3}

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1. National MS Society Brochure. Disease Modifying Therapies for MS. <http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-The-MS-Disease-Modifying-Medications.pdf>. Accessed January 2020.
2. Kappos L, Cree B, Fox R, et al. Siponimod versus placebo in secondary progressive multiple sclerosis (EXPAND): a double-blind, randomized, phase 3 study. *Lancet*. Published online March 22, 2018. [http://dx.doi.org/10.1016/S0140-6736\(18\)30475-6](http://dx.doi.org/10.1016/S0140-6736(18)30475-6).
3. Mayzent® (siponimod) Summary of Product Characteristics. Novartis International AG. January 2020.

Professor Michael Hanna elected to Academy of Medical Sciences Council

Professor Michael Hanna, Director, UCL Queen Square Institute of Neurology, has been elected to the Academy of Medical Sciences Council. The Academy is governed by a Council of 18 Fellows including six Honorary Officers whose role is to provide strategic advice to the Academy. New members are appointed at the AGM and Annual Fellows' meeting and serve for three years. Professor Hanna joins Professor Elizabeth Fisher on the Council.



Salford Royal Parkinson's disease expert Dr Monty Silverdale has been named Greater Manchester's Investigator of the Year at the prestigious 2019 NIHR Greater Manchester Clinical Research Awards

Consultant Neurologist Dr Silverdale is leading some of the most exciting and promising Parkinson's disease research that is going on globally.

He is lead neurologist on the 'scent of Parkinson's' study using skin chemicals as a novel way to diagnose Parkinson's disease and is an expert on pain in Parkinson's, a less well known but highly debilitating consequence of the condition.

He is also the CRN specialty lead for dementias and neurodegeneration, lead neurologist on the Greater Manchester Deep Brain Stimulation Programme, and Chair of the UK Parkinson's disease Clinical Studies group, which organises Parkinson's disease research throughout the UK.



Professor Sarah Tabrizi receives Yahr award at World Congress of Neurology 2019

Professor Sarah Tabrizi was presented with the award for her contribution to Huntington's disease (HD) research after giving the 2019 Yahr Award Lecture.

Her lecture highlighted news of a potential treatment for HD, presenting exciting data from the ground-breaking antisense oligonucleotide trials for HD as recently published in the NEJM. She also presented other novel ways of targeting the disease causing mutant HTT including post-transcriptional Huntingtin lowering approaches, such as RNA interference, antisense oligonucleotides, and small molecular splicing modulators; DNA targeting techniques, transcription activator-like effector nucleases, and CRISPR/Cas9.

The development of objective biomarkers of disease and HTT-lowering outcomes, as well as improving delivery and distribution of therapies, has brought them to the forefront of Huntington's disease research, including clinical trials in patients.



Dr Penny Trayner Wins The 2019 Mike Barnes Innovation Award

Dr Penny Trayner, Paediatric Clinical Neuropsychologist at Clinical Neuropsychology Services Ltd is the recipient of the 2019 Mike Barnes Innovation Award for the development of Goal Manager, cloud-based software that supports key goal setting processes for Acquired Brain Injury (ABI) neurorehabilitation, including multi-disciplinary team (MDT) assessment, planning, review, communication, and evaluation. Miss Merryn Dowson, Dr Trayner's Assistant Psychologist, received the Award in London last week at the 11th Annual Conference of the United Kingdom of Acquired Brain Injury Forum.

The Mike Barnes Award for Innovation acknowledges, recognises and rewards an innovative project or concept that impacts on individuals with ABI. It is sponsored by Cygnet Health Care, in collaboration with the National Institute for Health Research (NIHR) Brain Injury MedTech Co-operative, one of eleven MedTech and In Vitro Diagnostic Co-operatives (MICs) funded by NIHR across the UK. The NIHR Brain Injury MedTech Co-operative works with patients, carers, NHS, charities, academia, inventors, small and medium-sized enterprises and business angels to support the development of new medical devices and healthcare technologies, improving the effectiveness and quality of healthcare services.

Goal setting is crucial in ABI neurorehabilitation. It requires collaboration within the MDT, service user motivation and progress tracking. Despite the extensive evidence base available, effective goal setting across services continues to be inconsistent and time consuming, leaving limited time for the MDT to work on achieving goals through therapeutic practice.

Commenting on the Award Dr Trayner said: "We are delighted to win this Award for our software which I developed from my clinical experience of working with MDTs over the past decade of rehabilitation practice. The aim was to make goal-setting easier, faster and more straightforward for teams and individual clinicians. We have been able to streamline gold-standard processes into one system, which is accessible from any web browser, anywhere in the world. Users can instantly record progress on goals, and the MDT is then always up-to-date. We have already seen huge benefit within our existing users, and are excited to share this tool with the rehabilitation community for wider patient benefit. Thank you to UKABIF for their support in driving the field forward through innovation, and we are very grateful for the opportunities this Award has given us."

The Award will provide the crucial investor support required to develop Goal Manager further, enable it to better accommodate the idiosyncrasies of services, and incorporate large scale usage.

Professor Angela Vincent receives the Research Recognition Award at the Annual Meeting of the American Epilepsy Society 2019

The AES Research Recognition Awards are given annually to active scientists and clinicians working in all aspects of epilepsy research. The awards recognise professional excellence reflected in a distinguished history of research of important promise for the improved understanding and treatment of epilepsy. These awards include a \$10,000 honorarium. The clinical science award was shared by Angela Vincent and J Dalmau.



Sleep disorders and the neurologist

"We see only what we know" Goethe



Kirstie Anderson,

BMedSci, MBBS, MRCP, DPhil (Oxon), runs the Regional Neurology Sleep Service with a clinical and research interest in all the sleep disorders. She is an Honorary Senior Lecturer at Newcastle University with an interest in the link between sleep and mental health.

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Abstract

Diagnosing sleep disorders requires a slight shift of focus to the dark side, the patients are by definition unreliable narrators – the whole point of sleep is that we are not really there when it happens. However, for the sleep clinic all you need is a short question list, often helped by the bed partner present and a very small number of tests. Sleep disorders are rewarding to treat and this article covers the basics for the jobbing neurologist.

Neurologists are trained to spot patterns, we live in a daytime world and the natural tendency is to force every symptom a patient gives you into a daytime diagnosis you are good at spotting. This is one reason sleep disorders are missed in the neurology clinic. Labels of "MS fatigue" rather than obstructive sleep apnoea and "absence seizures" rather than microsleeps on sedative drugs are incorrectly applied. Patients are part of the problem, by definition you are an unreliable narrator when you are asleep and many of the sleep disorders are chronic and slowly worsen over time in people who otherwise look well. The average delay to diagnosis for narcolepsy is 7 years even in recent case series. This is a shame as sleep disorders have highly effective, often life transforming treatment, it is worth learning to recognise them.

A short list of questions can help (Table 1) for anyone who complains of poor sleep with either daytime sleepiness, insomnia, or things going bump in the night (parasomnia). This does not include those who fall asleep without delay, awake refreshed and can share a bed with someone without any protest from their bed partner. People who thought they were fine until they bought a fitbit that told them they got

no deep sleep simply need to take off their fitbit at night and keep it for their 10,000 steps a day. Recent validation studies of smartphone apps and wrist worn lifestyle accelerometers emphasise that they don't provide accurate sleep stage detection but can worsen insomnia. They also bring high intensity light and daytime life into the bedroom.

Two different male patients attending the Sleep Clinic in Newcastle both told a near identical story. An insidious, progressive story over some years of violent dream enactment behaviours caused by failure of the inhibitory pontine signal to spinal motoneurons that normally renders us atonic during our dreams. Both men were married and in their mid 50s with injury to wives as the reason for referral. This is typical REM sleep behaviour disorder, first described in just 5 patients (4 of whom were male) by Carlos Schenck in 1986.

Large case series over the last 30 years have highlighted this as a common parasomnia in 1.0 % of older men with at least 70% injuring themselves or their bed partners. However, there is a differential including significant sleep apnoea (look for significant daytime sleepiness and snore), and certain antidepressant medications. Ideally an in-patient video sleep study should be used to confirm the diagnosis. As a minimum, a respiratory sleep study can exclude OSA. Without any large RCTs to guide therapy, melatonin (dose range 2-10mg) or second line clonazepam (0.5mg to 2mg) is effective in 70-85% of patients and decreases injury. RBD is now well-recognised as a prodromal symptom for subsequent neurodegeneration and in particular alpha synucleinopathies. A recent longitudinal study looking at 1242 patients from 24 different sleep services showed a conversion rate of 7% a year and a 73%

Table 1. Questions for a sleep history

Do you snore loudly? Apnoeas? STOP-Bang screen for OSA, consider sleep study if score >3.
Restless legs – do you need to move your legs in the last hour before bed or when first in bed.
What drugs and when – include caffeine, alcohol and nicotine.
"Take me through a typical 24 hours" include lights out and lights on time.
"Can you get through the day without napping?"
Napping – average duration and examples of when.
Night sleep fragmented? Vivid and frequent dream recall.
Parasomnia and first or second half of the night?
Epworth sleepiness scale, sleep diaries

chance of conversion by 12 years. Careful population screening shows men and women are equally affected but men present (or are recognised) far more in sleep clinics.

NREM parasomnia includes sleepwalking, night terrors and confusional arousals and unlike RBD, have a younger age of onset, wax and wane over time with limited recall. Events are variable and many will only present after injury or with new partner (or new baby) in the house. Treating daytime anxieties, keeping sleep time fixed and stable and time can be the best therapies. Many simply need reassurance but Table 2 below summarises key difference between NREM, REM and nocturnal seizure.

Younger and very sleepy people may well have narcolepsy – the typical age of onset is 14 with a smaller group presenting later in their mid 30s. The classical tetrad is daytime sleepiness, cataplexy, hypnagogic hallucinations and sleep paralysis creating a disturbingly dream filled night. This is still often missed in clinic as symptoms evolve over weeks and months. Sleep attacks are rare and not specific to narcolepsy. A fragmented night is one additional important clue, long deep sleep is unusual in narcolepsy. Power naps are often effective and part of treatment. Cataplexy just looks odd if you haven't seen it before and it is worth looking at the published teaching videos and asking for home videos. Misdiagnosis as dissociative events can happen if the emotional trigger is missed. Children in particular can have pseudomyopathic faces and near permanent tongue loll and clumsiness.

Narcolepsy in humans is autoimmune with selective degeneration of hypocretinergic hypothalamic neurones. This allows a definitive measurement of cerebrospinal fluid (CSF) hypocretin levels and undetectable levels below 110pg/ml are now sufficient

for diagnosis. If there is difficulty accessing polysomnography and multiple sleep latency tests, CSF hypocretin provides a useful alternative.

Education around the condition remains key for the patient. Stimulants decrease sleepiness and improve daytime function with modafinil (100-400mg a day) remaining first line and the only licensed therapy within the BNF. It has a relatively long half life, good safety profile and low risk of dependence or habituation although blood pressure needs monitoring. Venlafaxine is first line cataplexy therapy despite lack of RCT data, the short half life may require either modified release preparations or tds dosing, patients should not stop abruptly or symptoms rebound. Methyphenidate is second line in adults but used more in children. Sodium oxybate has limited access for adults but provision for post pubertal children with NHS England funding. Pitolisant as a novel histaminergic inverse agonist is now available within secondary care in the UK as a long acting, well tolerated stimulant.

Restless legs syndrome was first described as a "snapping of the tendons" by Willis but eloquently characterised in detail by Ekblom in 1944. The associated and strikingly periodic limb movements of sleep were described in 1967 and are seen in at least 80% of patients in the sleep lab. There is no other "mind the gap" movement disorder. The diagnosis is usually clinical with careful history excluding other neuropathic pains. The only blood test the author performs is serum ferritin (replace if below 75). Antihistamines, beta blockers, dopa depleting medication and nicotine all aggravate RLS and should be reduced or removed if possible.

Ropinirole, rotigotine and pramipexole are licensed therapies with effective short and medium term benefit in RCTs but there

are now well recognised side effects from all dopamine agonists with impulse control disorder (10-13% of those treated for RLS) and augmentation (occurring at a rate of 7% a year – worsening symptoms, need for more medication and spread of RLS to other body parts). Therefore all need careful ongoing screening for impulsive behaviours. Low dose, once daily gabapentin or pregabalin may be safer and also show benefit in RCTs although remain off license in the UK.

Obstructive sleep apnoea occurs in at least 10% of men and 5% of women over 40 and overweight, but in a surprisingly high 30% of chronic MS patients and in 30-50% of the pain clinic often with help from opioids and gabapentinoids. The simplest screening tool is the STOP-Bang, those scoring over 3 and sleepy should be referred to the local respiratory sleep service. We should all support GPs to reduce inappropriate opioids, the mechanisms of worsening pain are identical to analgesic overuse headache but often with additional daytime sleepiness.

Sleep disorders in the neurology clinic are common with 30% of chronic MS and treatment resistant epilepsy patients having moderate or severe OSA. This tends to be true of any long term conditions decreasing activity and needing drugs that cause weight gain or decrease muscle tone.

Bedtime stories are fascinating, usually treatable and so worth spending a little time learning about. For normal brain function, we all need to sleep well.

Further bedtime reading

1. Postuma RB, Iranzo A, Hu M. Risk and predictors of dementia and parkinsonism in idiopathic REM sleep behaviour disorder: a multicentre study. Brain. 2019 Mar 1;142(3):744-59.

2. Reading P. Update on narcolepsy. Journal of Neurology. 2019;266:1809-15.

3. <https://irlssg.org> The International Restless Legs Society Study Group.

Neurologists are trained to spot patterns, we live in a daytime world and the natural tendency is to force every symptom a patient gives you into a daytime diagnosis you are good at spotting. This is one reason sleep disorders are missed in the neurology clinic.

Table 2. Distinguishing the bumps in the night			
	NREM	REM	Nocturnal seizure
Duration	5-15 mins, hard to wake	Brief seconds to a minute, easy to wake	Seconds, easy to wake
Stereotyped	No	No	Yes
Dream recall	Sometimes	Yes	No
Wax and wane	Usually	No	Yes
Timing in the night	More likely first hour	Within first hour is rare	Variable but at sleep onset/offset
Age of onset	Childhood 80%, under 40 typical	Most >50 yrs, childhood rare	Variable but younger onset



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📅 Date: 8-9 October 2020

This residential MasterClass is for secondary care clinicians, including nurses, old age psychiatry consultants and registrars.

Alzheimer's Advanced MasterClass

📅 Module 1: 8-9 July 2020 + Module 2: dates TBC (approx. 6 months later)

This training course is aimed at consultants and higher trainees in both behavioural neurology and old age psychiatry.



Parkinson's Foundation MasterClass

📅 Date: 15-16 September 2020

For non-final year registrars, old age psychiatry registrars, Parkinson's nurses within the first 18 months of post, occupational therapists, speech and language therapists, pharmacists, clinical fellows and clinical lecturers.

In the rehabilitation section of this edition we have chosen to focus on 'alternative' therapeutic approaches utilising music or animals. This reflects a growing interest in the importance of providing a stimulating therapeutic environment for patients as they undergo rehabilitation. There is evidence that patients undergoing inpatient rehabilitation are bored¹ and inactive.² Patients treated in 'enriched' environments show greater levels of physical activity, social interaction and cognitive activity.³

Importantly, in the current financial climate, this was achieved without increasing staffing numbers; it is a change in mindset and also having availability of resources to support these interactions. Environmental enrichment can include provision of equipment to enhance activity away from the bedside e.g. i-pads, books, puzzles, newspapers, games, music and magazines. It can also include provision of daily group sessions, with a varied focus,

for example: self-management education, emotional support, communication, physical activities. Some of the interventions in studies on stroke units may already be occurring on rehabilitation wards e.g. communal mealtimes, but there is still scope to look at relatively easy and cheap changes that could enhance a patient's rehabilitation journey and potentially improve rehabilitation outcomes and reduce length of stay. It is essential that rehabilitation environments enable people to continue to participate in meaningful activities and supporting interaction with family members as this can facilitate the transition to living with what is often a long term disability. Being hospitalised following an acquired brain injury entails many losses – loss of function, loss of independence, loss of role within family and society and a loss of identity. Physiological losses are compounded by a physical separation from family and also in some cases a virtual separation (the single most common complaint

on our ward used to be the lack of wifi signal). Loss of access to hobbies and cognitive stimulation from work often compounds the boredom. Hobbies and activities that interest people are intrinsically more rewarding and motivating than therapist-driven exercises. Diane Playford at the recent BSRM meeting spoke about the importance of 'play' or non-structured activity during rehabilitation and encouraged us to think of ways of incorporating more opportunities for play within our units. I hope these two articles will continue to stimulate that discussion.

Emily Thomas, Rehabilitation Editor.

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Why include music therapy in a neurorehabilitation team?

Abstract

Interdisciplinary neurorehabilitation programmes can be enhanced by including music therapy as music interventions can incorporate a patient's goals across behavioural domains. Neurologically, music is intrinsically motivating, drives motor function and elicits emotional responses. Incorporating live music delivered by trained and qualified professionals ensures interventions are tailored to patients' needs and goals, assisting with engagement and adherence to treatment. The evidence for the effects of music therapy in neurorehabilitation is reviewed, with reference to a recent Cochrane Review.

Summary

- Music therapy with neurological populations typically engages the patient in active music-making, with the therapist playing live music and adapting musical components moment-by-moment to both meet patient needs and to challenge the patient to reach goals.
- In neurorehabilitation, interventions range across song-writing to address psychosocial needs, singing and vocalising exercises to target communication goals, and playing instruments or moving to music to meet motor goals.
- Neurologically, music is intrinsically rewarding and motivating, activating neural networks

throughout the brain that influence non-musical behaviours, and resulting in changes to brain structures.

Music therapy: what is it and what is involved?

The rationale for including music therapy as part of an interdisciplinary rehabilitation programme may not be immediately obvious: unlike other professions that address function within a more clearly defined domain (e.g. physiotherapy for movement disorders; speech and language therapy for speech/language disorders; psychology for cognitive disorders) music therapy addresses function across domains. As defined, music therapy is the clinical and evidence-based use of music interventions to accomplish individualised goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy programme.¹ A common misconception is that music therapy is passive listening to recorded music. However, when delivered by a trained professional, music therapy typically actively engages the patient in live music-making, targeting active health goals, with the therapist adjusting musical parameters (tempo, dynamic, rhythm, pulse, melody, harmony) moment-by-moment in immediate response to the patient's functioning.

Internationally, professionals trained as music therapists are required to adhere to professional standards and codes of conduct: in the UK, music therapists are registered with the Health and Care Professions Council. Music therapy interventions are distinguishable from recreational activities, as they are individually tailored to the individual, goal directed and planned by a health professional. Interventions vary considerably, even when targeting goals within the one domain (i.e. motor; psychosocial; communication) but fall into two broad categories: active or receptive methods.² Active methods used in neurorehabilitation include: song-writing; music-making using acoustic or digital MIDI instruments; movement to music including gait training to rhythmic music or metronome; and singing or vocalising. Receptive methods include: music listening to live or recorded music; and imagery to music. Dosage for effective music interventions vary widely in terms of the number and frequency of contacts, the duration of individual contacts and course of therapy, and the mode of delivery (individual or group).² Dosage is dependent on the targeted outcome, stage of rehabilitation and setting, so standard recommendations cannot be made.

Why include music therapy in a neurorehabilitation team?

The theoretical rationale for using music in neurorehabilitation centres upon music's innate competencies within humans, its cross-cultural purpose for social bonding across cultures, and its neurological capabilities in both healthy and neurologically damaged populations. Music is a universal phenomenon that exists in all known human societies and is considered distinctive to the human condition.³ Cross-culturally, humans engage in musical activity through singing and instrument playing as part of creative play and within ritual. So music is a familiar, meaningful activity with many inherent associations, even for those who are musically untrained. Music is also a social activity, a medium for engaging with others in meaningful collective practices⁴ and assists with managing social relationships.³ Thus, it facilitates social bonding and interaction as music-making is rarely a solitary activity. In western societies, music-making is realised through singing in choirs and ritual practices and playing instruments in bands and orchestras. Group singing is conducive to social bonding⁵ and has been found to be a stress-reducing activity as measured through reductions of adrenocorticotrophic hormone,⁵ cortisol and cortisone.⁶

However, the strongest argument for including music therapy in neurorehabilitation lies in its neurological benefits. Neurologically, music is intrinsically rewarding as it activates brain regions involved in reward, motivation, emotion, and arousal.⁷ Cortical changes in brain damaged patients during music interventions indicate activation of bilateral networks across the frontal, temporal and parietal lobes, cerebellum and limbic areas, stimulating

cognitive, motor, and emotional processes.⁸⁻¹⁰ When integrated with repetitive rehabilitation exercises and drills, music that is tailored to an individual's performance can enhance the motivation to sustain engagement and may improve patient mood and enhance motivation.¹¹

Music therapy interventions in

neurorehabilitation: practice and evidence

Music boosts cognition in the brain damaged patient, with reported effects on arousal, attention, orientation, memory, executive function, spatial neglect, and mental flexibility. For patients with Disorders of Consciousness (DOC), maintaining arousal is a significant problem and can interfere with optimal engagement in rehabilitation. Using music that is salient to the patient has been found to promote behaviours indicative of arousal and selective attention,¹² increase behavioural responses that indicate discrimination¹³ and awareness.¹⁴ Music therapy within interdisciplinary care may prime patient responsiveness in DOC,¹⁵ which is particularly useful when part of co-treatment: a music therapist will play live music that is personally salient to the patient, adjusting musical parameters to help the patient achieve and maintain an optimal state of arousal so as to engage in treatment sessions. Music has also been found to improve orientation for patients in post-traumatic amnesia.¹⁶ Following middle cerebral artery stroke, music interventions have been shown to be superior in enhancing cognitive recovery, more specifically verbal memory and focused attention, when compared to a language intervention (patient selected audio book listening) or a control condition (standard rehabilitation).⁸ Similar results have been found with mild traumatic brain injury patients, where music training in the form of eight weeks of piano tuition resulted in significantly improved results in executive functions related to attention, learning strategies and memory retrieval.¹⁷ Thus, music interventions have demonstrated positive effects across the spectrum of brain damage.

Of all behavioural domains with neurological populations, the strongest evidence for music interventions is with motor disorders. Motor regions within the cortex are sensitive to and driven by auditory stimuli as the auditory system processes temporal information rapidly and precisely, creating entrainment between a rhythmic signal and movement.¹⁸ In healthy subjects, movement to music results in superior physical performance: running for longer, lower perceived exertion, and slower exhaustion.¹⁹ These beneficial effects are increased when agency is incorporated into a workout, that is, that the physical movements result in musical sounds.²⁰ These observations support the growing body of research examining the influence of music with a strong beat on gait disorders and upper limb function in adults with stroke and acquired brain injury. A Cochrane Review examined the effects of rhythmic auditory stimulation (RAS) on gait velocity,

cadence, stride length, stride symmetry, gait and balance.² RAS is a therapeutic intervention using rhythmic pulse to improve gait or gait related aspects of movement. Using live music, the therapist can embed the rhythmic pulse into the music for the patient to move to, or a metronome alone can be used. Based on 10 randomised controlled studies (n=298) the meta-analysis found beneficial effects for RAS on gait velocity, stride length, gait cadence and general gait in people with stroke, although the degree of improvement across studies was inconsistent.² Subgroup analyses indicated that RAS interventions using live music with the beat embedded in the music may be more effective than using a metronome alone in addressing gait velocity and cadence. These findings highlight that although RAS can be implemented within interdisciplinary rehabilitation by non-music professionals using a metronome, the inclusion of a music therapist in the rehabilitation team using live music may enhance the intervention's benefits. Music provides an intrinsic motivational reward, and using live music enables components (such as tempo, dynamic tension, harmonic tension and resolution, melodic direction) to be adapted in the moment to the patient's movements, driving these movements to goal attainment.

Music interventions are used to rehabilitate upper limb function following stroke, measuring outcomes such as timing of movement, strength, hand function, manual dexterity, range of motion and elbow extension angle² and often in co-treatment with occupational therapists. Interventions typically involve the patient playing strategically placed musical instruments in live music making: the therapist commonly manipulates rhythm and tempo in the accompanying music to guide the patient's movements, but harmonic and melodic tensions are also used. A number of studies have examined neural reorganisation during these interventions, noting coupling between the motor and auditory cortices.¹¹ The benefits for involving music therapy in team treatment include motivation and adherence to treatment of motor disorders.²¹

Communication outcomes are frequently targeted with music following stroke and traumatic brain injury, as it has long been noted that people with severe non-fluent aphasia have greater success when singing lyrics than speaking the same words.¹⁰ Although speech and music are neurologically distinct, they share pitch, timing and timbre cues to convey information at an acoustic level and at a cognitive level both demand complex cognitive skills: memory, attention, and the ability to integrate acoustic events and perceive these according to rules of syntax are required by both.²² Music, like language, has structural rules for production suggesting a deep connection between the two within the brain. Intensive music interventions to address language production with people with severe non-fluent aphasia have resulted in neuroplastic changes to connections across brain regions.¹⁰ The acts of speech and singing additionally share musculature for

respiration, phonation, articulation and resonance.²³ Music therapy interventions address communication goals through singing and vocalising, often in co-treatment with speech and language therapists. Singing interventions address non-fluent aphasia, dysarthria, dyspraxia, dysprosody and dysphonia measuring outcomes such as words produced, speech intensity, naturalness and intelligibility, rate control, articulation, phonation and prosody.^{2,24} Melodic intonation therapy is an intervention frequently used to target language production in expressive aphasia, engaging right-hemispheric structures through tapping of the left hand and intoning words in a melodic contour that imitates speech prosody.¹⁰ Numerous case reports describe the benefits of a number of music interventions to improve communication, supported to some extent in research suggesting benefits to overall communication, naming and repetition.² Further research would consolidate these findings and improve the widely varying protocols that have been reported.

Lastly, music therapy interventions are reported to improve psychosocial functions such as behavioural outcomes, emotional needs, mood, well-being, social skills and quality of life.² Psychosocial sequelae are integrally related following brain injury: communication or behavioural difficulties impact upon social relationships, risking feelings of isolation and depressed mood, reducing quality of life. Music therapy can reduce agitation in patients with post-traumatic amnesia.¹⁶ The intersectional nature of psychosocial subdomains can be addressed through therapeutic music-making as a meaningful social experience that enhances social bonding³ and stimulates emotional experiences. Music therapy will typically use active music interventions such as song-writing, improvisation and song-singing to address mood, identity reconstruction and emotional expression in neurorehabilitation.² These can be powerful interventions when delivered in groups and may also incorporate members of the patient's social support network. Individually tailored

music listening programmes in the acute recovery phase post-stroke have resulted in less depressed and confused mood states than standard rehabilitation.⁸ More research is needed examining the effects of music interventions on all aspects of psychosocial functioning.

Conclusions

Music provides a familiar salient stimulus that activates widespread neural activity and has the potential to be harnessed to improve functioning across all the behavioural domains, including motor, cognition, communication and psychosocial. Thus, music therapy is well-placed as an intervention in neurorehabilitation. Music is also ubiquitous and easily accessible with the swipe of a screen, but its use is not without risk, particularly the possibility of triggering strong emotional reactions. The application of music interventions in neurorehabilitation thus requires planned and careful application with vulnerable populations by professionals trained in its use.

Music boosts cognition in the brain damaged patient, with reported effects on arousal, attention, orientation, memory, executive function, spatial neglect, and mental flexibility. For patients with Disorders of Consciousness (DOC), maintaining arousal is a significant problem and can interfere with optimal engagement in rehabilitation.

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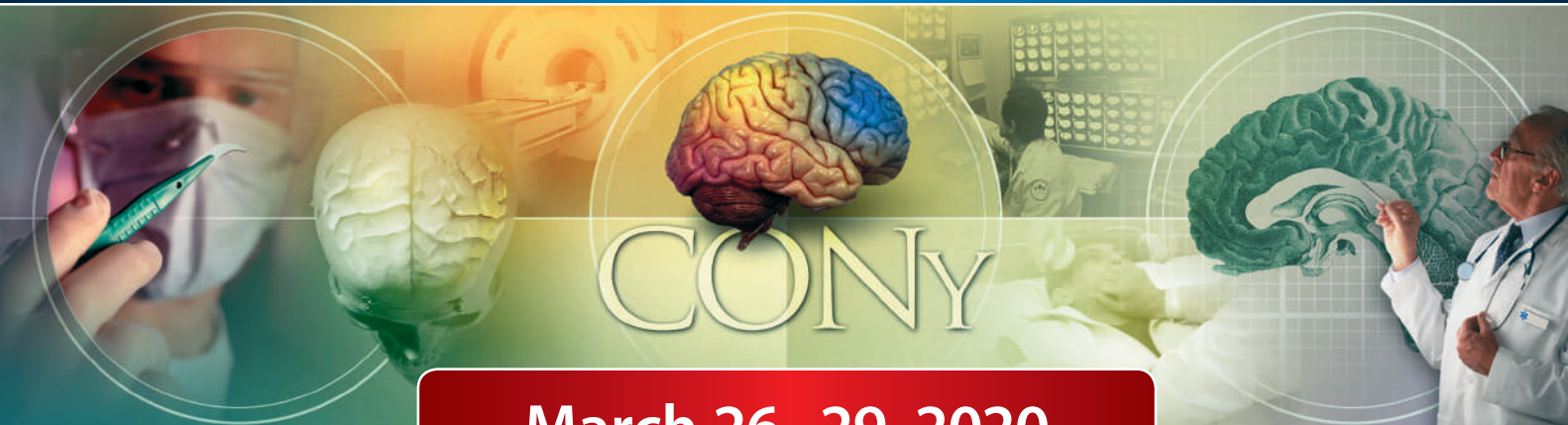
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Human animal interaction, animal assisted therapy and pet ownership in neurorehabilitation

Abstract

Human animal interactions (HAI), animal assisted therapy (AAT) and pet ownership can confer huge benefits for patients undergoing neurorehabilitation, in inpatient and outpatient settings. However, these must be weighed against potential risks and disadvantages both for the patient and for the animal. The field of HAI in neurorehabilitation has great potential for research.

Key points

- Interactions with therapy animals and patients' own pets can improve social interactions, mood and engagement with rehabilitation
- Pet ownership has many positive associations with health and wellbeing
- Asking patients about their pets can improve communication and compliance
- Good links should be established with hospital volunteer services, charities and infection control services to enable smooth running of therapy animal visits to inpatient units.

Introduction

It's 2014. I am a Registrar working on a busy inpatient neurorehabilitation unit. Jon* is pacing around the unit. He has suffered a severe traumatic brain injury. He used to be a keen musician and long-distance walker. He is a retired manager and a much-loved husband, father and grandfather. His brain injury has left him with significant neurological deficits, including cognitive and speech impairment and, unsurprisingly, associated agitation, low mood and anxiety. He's been with us for several weeks now and despite the best efforts of the multidisciplinary team, he spends his days (and parts of his nights) almost constantly on the move, unable to settle, seemingly looking for something or someone. He can't tell us what – the only thing he reliably says is "Nooooo". Our paths cross by the reception desk, as the front door opens and Molly, a therapy dog on her first visit to the ward, comes in with her owner. Mid "Nooooo", Jon stops, turns, and hurries towards Molly. He drops to his knees, throws his arms around her, and spends the next 15 minutes stroking and cuddling her. I've always been a bit sceptical about describing someone's face as "lighting up" – but Jon is transformed. It's not a long-lasting effect, but that interaction with Molly has given Jon 15 minutes of distraction and joy in what was clearly otherwise a distressing, confusing and overwhelming world.



Figure 1: Lizzie, PAT dog (picture by Kim Tooze, Therapy Practitioner Assistant, King's Lodge).

HAI and AAT

Observing the interaction between Jon and Molly first stimulated my interest in human-animal interaction (HAI) and animal-assisted therapy (AAT) in neurorehabilitation. At King's Lodge Neurorehabilitation Unit in Derby, where I currently work, we have regular visits from a therapy dog and a range of therapy birds. Lizzie is a beautiful golden retriever who attends the ward on alternate weeks with her human, Jill, representing the charity Pets as Therapy (PAT). A recent service evaluation showed that patients enjoyed spending time with her, wanted to spend more time with her, and felt that Lizzie's presence in therapy sessions motivated them to do their therapy and helped their rehabilitation. Staff members unanimously agreed that Lizzie helped patient moods and commented on other benefits from Lizzie's presence, including opportunities for "hidden" therapy (spontaneous speech, social interaction, motor function such as throwing a ball or grooming Lizzie; sensory function through stroking her). The primary negative comments were around insufficient time to spend with Lizzie! Workers from a local bird charity (Woodie's

Table: Examples of how therapists have successfully integrated therapy dog / birds into sessions to address specific issues. Italics indicate quotes from staff members taken from recent service evaluation activity

Health condition	Body structure / function impairment	HAI / AAT Activity
Guillain Barré syndrome	Motor weakness upper limb	Holding progressively larger birds for progressively longer periods
Intracerebral haemorrhage	Visual inattention / neglect	Patient encouraged to walk with Lizzie's lead held in the hand of the neglected side, motivating him to scan more to that side when mobilising to improve safety
Stroke	Dysphasia	Encouraged to say names / give simple commands to dog or bird – a therapist reported: <i>"having a patient with severe aphasia / dyspraxia be able to say Lizzie's name with family there to watch was extremely rewarding as a professional and family were very grateful"</i>
Traumatic brain injury	Low mood	<i>"Helps to provide variety to the patients' experience when on the ward, increasing opportunity to access enjoyable activity, which we know can benefit mood"</i>
Posterior circulation stroke	Ataxia	Grooming dog / stroking bird
Multiple sclerosis	Poor confidence – social interaction	Taking animal / bird (accompanied by therapist and handler) around or off the ward, encouraging conversations with patients, staff and visitors
Hypoxic brain injury	Poor confidence – gait	Patient had been assessed by therapists as being able to walk safely without stick or other aid but was extremely nervous about doing so. She walked the length of the ward with Lizzie on a lead and discarded her stick thereafter.

Wings) bring a range of tame birds to the ward and patients spend time holding them, stroking them, talking to them and helping them do "tricks". Watching a laughing patient drive her wheelchair down the corridor with a cockatoo on her shoulder is a truly uplifting experience in the middle of a ward round!

Members of our multidisciplinary team were therefore heartened – but unsurprised – to see the recent publication in Scientific Reports, where Hediger and colleagues reported a randomised controlled trial of AAT in 19 patients with acquired brain injury. Social interaction was significantly higher during AAT sessions compared to conventional therapy sessions, with concomitant increases in verbal and non-verbal communication, self-reported mood and self-reported motivation.¹ There were no longer-term effects, or effects outside the therapy sessions, reported however.² It is relatively unusual to see such a report, as to date there has been an arguable deficit in the field of research into AAT and HAI in neurorehabilitation.³ Some research studies have been conducted in related fields, however, and their findings suggest that AAT could be of great benefit in neurorehabilitation – for instance, studies showing improvements in social interaction and reductions in agitated behaviour in dementia;⁴ improvements in depression⁵ (which is commonly seen in rehabilitation and recognised to reduce participation⁶) and even alterations in stress- and mood-related hormones⁷ and EEG signals.⁸ All of these could potentially be extrapolated to, and could be fertile research areas in, the setting of neurorehabilitation.

Pet Ownership

While patients' own pets are unable to attend our unit, we encourage families to bring pets to the hospital grounds, where many emotional reunions take place. Promises of pet visits can be a strong motivational tool, and a relative commented recently that Sam* showed much



Figure 2: Birds from Woodie's Wings with therapists and patients on King's Lodge Neurorehabilitation Unit (picture copyright University Hospitals of Derby and Burton Communications Team with consent given to reproduce).

more spontaneous movement and speech when interacting with his dog in the hospital garden than he typically does on the ward.

Indeed, the benefits of HAI are not restricted to the inpatient setting. It is becoming increasingly recognised that pet ownership has many benefits. Pet owners with chronic diseases report that their pets improve their mood and quality of life and provide strong relationships, non-judgemental intimacy, physical contact and a sense of routine and self-efficacy.⁹⁻¹¹ Rehabilitationists will recognise all of these as vital components for living well with chronic illness and disability.

Interestingly, a recent study also suggested that asking patients about their pets in an outpatient setting improved rapport, communication and therapeutic alliance, and improved clinicians'

understanding about their patients' activities and lifestyles.¹² In a context like neurorehabilitation, such information can be invaluable on several levels. Someone who is regularly walking a bouncy young golden retriever is likely to be independent and active, whereas someone who has responsibility for a cat or elderly lapdog needs to be able to structure routines around feeding, toileting and grooming.¹³ Several patients have reported to me that their pets are a significant protective factor for their mental health – even, in some cases, a key reason not to consider self-harm or suicide. One must also therefore consider the importance of asking about pet loss or separation, which could precipitate mental health problems¹⁴ in patients who by nature of having chronic illness or conditions are already vulnerable and at risk of depression.¹⁵

Potential risks

Of course, no intervention can be guaranteed to be without risks or potential adverse effects and all of these must be weighed up against any theoretical benefits. All animals associated with Pets as Therapy are health and temperament checked, and for inpatient visits, our unit follows strict precautions (including no exposure to patients with open wounds; animals not to go into patient areas; rooms where the animals are seen are thoroughly cleaned afterwards). Naturally, those patients with animal fears or allergies should not be exposed, and there is a risk of trauma, including

bites, or even infection transmission.¹⁶

Pet ownership is also not without complications and problems – whether that be financial implications, worries about pet separation, illness or death,^{13,17} or the stress related to having the puppy of your dreams chew their way through your furniture, shoes and bank statements!

One cannot suggest that pet ownership or HAI is a universal panacea, and each individual (with or without their healthcare practitioner) should consider the relative risks and benefits before proceeding with HAI, AAT or pet owner-

ship. In particular, the health and welfare of any animals must be paramount – Jill reports that Lizzie happily jumps into the car when she is told that she is coming on therapy visits, and her joyfully thumping tail when she is on the ward supports this. However, any signs of distress or discomfort in animals should result in their immediate removal from the situation. Similarly, anyone taking on pet ownership should ensure that they are well informed of the physical, mental and emotional needs of the pet and that they can meet those needs.

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An expert opinion: Rehabilitation options for people with polyneuropathy

Key take home messages:

- Aerobic exercise and resistance training of less affected muscles show moderate effect in people with polyneuropathy
- Resistance training for more affected muscles may show improvement if the muscle scores above 4/5 MRC score at baseline. More trials are required
- Orthotics can be used to treat a range of gait deviations for people with polyneuropathy.
- A thorough assessment and identification of patient goals are key to a successful orthotic prescription
- Early education is essential in providing strategies aiming to maintain hand function for people with polyneuropathy
- Consider splinting to support grip patterns for people with neuropathy with mild to moderate impairment

Abstract

Polyneuropathies encompass a number of diseases of the peripheral nerves. Causes vary, and some types of polyneuropathy have a chronic disease course, and some have acute onset. Polyneuropathies, such as Guillain Barré Syndrome, improve after acute deterioration, but some people are left with longer term disability.

Physical management to manage longer term impairments and maintain function, are gathering evidence of efficacy, though trials remain small in number and size. Exercise trials show some positive improvements in proximal muscle strength, aerobic capacity, balance and distal strength in children. People with polyneuropathy often present with distal weakness and joint malalignment. Orthotics interventions may address these impairments and can vary from ankle foot orthoses to insoles. Weakness and sensory impairment also lead to altered hand function which can be addressed by adaptive strategies and exercise.

People with polyneuropathies can benefit from rehabilitation interventions through addressing the impact of impairments and compensatory strategies necessary for optimised function.

Introduction

Polyneuropathies are common neurological disorders affecting the peripheral nerves. There are a number of causes of damage to these structures, and they can be categorised as inherited: e.g. Charcot-Marie-Tooth disease (CMT); or acquired: e.g. diabetic or inflammatory neuropathies. Motor and sensory impairments are commonly encountered in these

conditions leading to altered balance, gait and upper limb function.¹ Inherited neuropathies tend to come on earlier in life and are slower progressing. Acquired neuropathies have a more variable rate of onset and disease course. Many polyneuropathies tend to affect the distal sensorimotor functions first, but inflammatory neuropathies can be patchy with earlier proximal involvement.

Common impairments are primary muscle weakness and wasting due to denervation, and impairments of proprioception and nociception. Deformities of the feet are associated with early onset of disease due to muscle imbalance and soft tissue shortening.² Altered hand posture and grip is also observed with greater weakness of intrinsic muscles.³

Rehabilitation interventions aim to optimise function, support weakness and accommodate deformity. Acute onset polyneuropathies, e.g. Guillain Barré syndrome, are often managed through the recovery phase with multi-disciplinary rehabilitation.⁴ There is evidence of good functional improvement and intensity of early intervention appears to be important to people with the disease.^{5,6} Not all people with GBS make a full recovery and some are left with long term disability. Other types of polyneuropathy are long term conditions. A vital component in maximising function and participation in people with chronic polyneuropathies is targeting rehabilitation interventions in an effective and timely manner. Although pathways of optimal physical management are not yet available, combinations of rehabilitative and management approaches are gathering evidence, specifically in exercise, orthotics and adaptive upper limb strategies.

Exercise in polyneuropathy

Exercise training to improve function for people with polyneuropathy falls into three main areas: aerobic training, general strength training and specific proprioceptive training. The overall evidence for the efficacy of exercise is limited, as demonstrated by systematic reviews,^{7,8,9} but it is an expanding area of research focus. In diabetic neuropathy, intensive aerobic exercise may regenerate intra-epidermal nerve fibre density in pre-diabetic metabolic syndrome, and walking activities can slow the progression of diabetic neuropathy.¹⁰ There are fewer studies in other rarer polyneuropathies, but cycle ergometry has been shown to improve cardiorespiratory fitness and fatigue in CMT.¹¹

There is more robust evidence for proximal muscle strength training in polyneuropathy with improved strength and function with struc-



Figure 1: Thumb splints to aid grip and hand function.

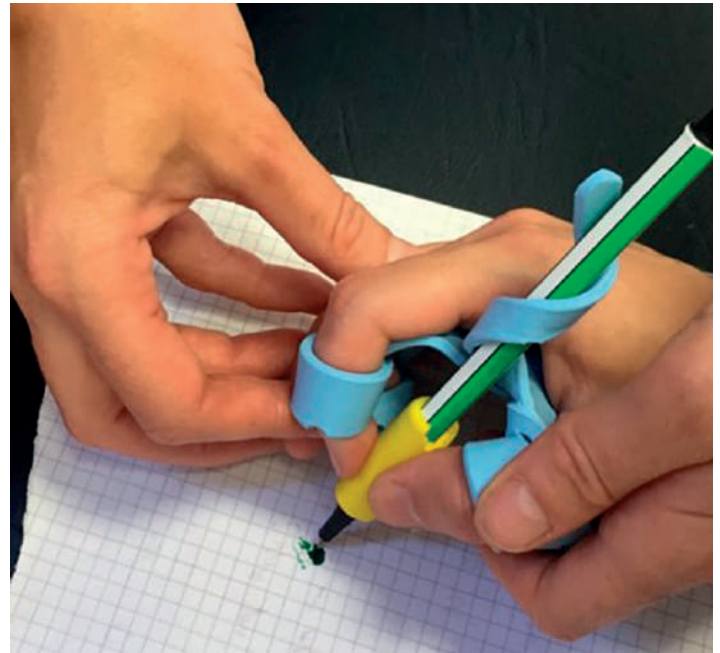


Figure 2: Customised hand splint to aid writing.

tured programmes.^{7,8} Most trials target the less affected muscles groups. A more recent study of distal strengthening in children with CMT showed sustained improvements over two years compared to controls who declined over the same period, as expected with the natural history of the disease.¹² This suggests that earlier interventions may impact disease progression, but this is yet to be explored in adults or in people with more severe weakness.

Specific balance training interventions have been explored in polyneuropathies, often as a combination of multi-sensory and proprioceptive exercises plus strength training. In diabetic neuropathy there is evidence of efficacy with this more standard type of rehabilitation, but also novel methods such as perturbation platforms, dynamic target tasks and dynamic movement control with activities such as Tai Chi.¹³ In the rarer neuropathies the evidence is more sparse, but positive effects have been seen with multi-modal training in sensory neuropathy¹⁴ and CMT.¹⁵

Orthotic interventions

Patients with polyneuropathy who are referred to an orthotics clinic can present with symptoms including weakness, malalignment of the joints, reduced balance or pain. These symptoms can lead to gait abnormalities and people with neuropathy often benefit from orthotic interventions. The International Organization for Standardization [Prosthetics and orthotics]¹⁶ defines an orthoses as 'an externally applied device used to modify the structural and functional characteristics of the neuromuscular & skeletal system'.

Ankle dorsiflexion weakness will lead to 'foot drop' and an increased risk of trips and falls. Plantarflexion weakness will result in reduced propulsion during gait. Both will lead to compensatory movement patterns and an

inefficient gait. Patients with CMT 1A have been found to have a higher energy cost of walking than healthy individuals even if they have very mild impairment.¹⁷

Orthotic prescription will be determined by a discussion with the patient and an assessment of gait kinetics, manual muscle testing and joint range of motion. Patient goals should be set and orthotic prescription agreed with the patient. Orthotic prescription may be influenced by patient preference to the detriment of gait biomechanics due to factors such as cosmesis, environment and footwear.

Ankle foot orthoses (AFO's) are commonly used for polyneuropathy patients with distal weakness. These can be custom made or off the shelf, and are usually made from either thermoplastic or carbon fibre. The style and rigidity of the device will be determined and must be considered carefully for the best outcome.

The optimum stiffness of AFO is related to factors such as muscle weakness, ankle joint range of motion and body weight.¹⁸ Increased AFO stiffness reduces ankle movement during walking. Stiffer AFOs limit peak knee extension and increase knee flexion, there is low evidence for its effects on hip or pelvis kinematics and kinetics.¹⁹ Due to ability to return energy for propulsion, carbon fibre AFOs may increase walking speed and plantar-flexor power compared to a thermoplastic AFO.²⁰ Some patients may also identify their walking problem as due to knee instability. This may be due to the knee giving way or related to hyperextension, which can cause pain. There is a lack of evidence on orthotics for the management of knee instability related to neuromuscular disorders on pain and falls²¹ but control of knee alignment through use of rigid AFOs or through knee braces can be successful.

Patients with polyneuropathy commonly

present with changes to the alignment of joints, which can lead to pain, instability or callous build ups under the feet. Custom insoles are an effective treatment of cavus foot pain and its associated limitation in function by reducing and redistributing abnormal ground reaction forces.²²

Management of hand weakness

Intrinsic muscles of the hand, dexterity, grip strength and sensory function are most commonly affected in polyneuropathies. These are key components of hand function.^{23,24,25} These studies report that activities which require finger grips such as pulp pinch and lateral pinch are the most limited. Often compensatory movement patterns develop as the level of impairment increases.^{23,26}

Despite the prevalence of hand dysfunction there is limited evidence base for upper limb rehabilitation in neuropathy. For upper limb orthotics Videler and colleagues concluded that a thumb opposition splint can be effective in improving upper limb functioning in their pilot study.²⁷ Opinion papers recommend adaptive equipment to compensate for hand deformities, sensory loss, and weakness and intervention should aim to preserve or enhance manual dexterity.²⁸

Recent guidelines published by the Charcot Marie Tooth Association (2018)²⁹ recommend the following interventions:

1. Resistance training for the hand and wrist muscles
2. Activities that engage hands in coordination, fine-motor and manipulation
3. Splinting to support hand function and/or to provide a stretch to prevent contractures
4. Stretching to prevent soft tissue shortening
5. Adaptive equipment when remedial options are no longer indicated

In the early stages of diagnosis, encouraging normal grip patterns aims to delay overreli-

ance on the stronger extrinsic muscles and encourage the use of the intrinsic muscles within activities. With mild weakness education alone can be effective in promoting precision grips. Where education is not adequate, functional splints are frequently used. Thumb spica splints can improve palmar abduction to facilitate pinch grip.^{27,29} Figure-of-eight splints provide stability at the proximal interphalangeal joint for pure pinch and finger push grips. Metacarpophalangeal joint block splints prevent hyperextension and can promote active interphalangeal extension during tasks such as typing. Custom made functional splints support more complex grip patterns such as a tripod grip for handwriting.

Acceptance should be considered when prescribing splints to ensure they are effective. Functional splints can hinder function if prescribed at the later stages due to established compensatory movement patterns which they are reliant on for function. Experience in other neuromuscular diseases has demonstrated splints are less successful with severe muscle wasting.³⁰

Splints are used for the prevention of contractures²⁹ and maintenance of skin integrity. Patients may find resting splints heavy and bulky and therefore customised lightweight resting splints which target the joints at risk may promote compliance.

Task adaptation and equipment is another

key component to promote hand function. This approach is useful for more severe weakness for maintenance of independence. Task adaptation is also beneficial in the early stages to help facilitate normal grip patterns and improve efficiency to limit the impact of muscle fatigue and altered sensation.

Summary

People with polyneuropathies can benefit from rehabilitation interventions to improve, maintain or support function. Understanding the impact of impairments and compensatory strategies necessary for function enables clinical reasoning and optimised outcomes.

People with polyneuropathy often present with distal weakness and joint malalignment. Orthotics interventions may address these impairments and can vary from ankle foot orthoses to insoles. Weakness and sensory impairment also lead to altered hand function which can be addressed by adaptive strategies and exercise.

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Physical disability, a mark of Cain? The impact of disability stigma on access to rehabilitation services



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Introduction

The World Health Organisation, (WHO), describes disability as a term covering “impairments, activity limitations, and participation restrictions”. In essence, disability is not just a health problem but also a reflection of the interaction between a person’s body, the society they live in and the environmental and social barriers these may create. More than a billion people (15%) worldwide are living with a disability. This number is growing as the ageing population and the number of people with chronic health conditions increase.¹ Learning that one has a disability or chronic health condition is a life-changing event in a person’s life. Kleinman² said that “the integrity of our bodies is so central to our belief system that it is often assumed that chronic illness is a betrayal of that fundamental trust”.

Rehabilitation medicine is concerned with the diagnosis and treatment of conditions that lead to disability and the active participation of people with disabilities to prevent secondary complications and optimise quality of life.³ Jennings⁴ said “To rehabilitate is to restore the power or capacity for living. Living does not signify merely biological life and function but it takes on a qualitative dimension. It is the restoration of the power of living well, living meaningfully that rehabilitation seeks”. With the right kind of rehabilitation, people with disabilities and chronic illnesses should be able to optimise physical and cognitive functioning as well as modify personal and environmental factors to ensure the best outcomes.⁵

There are many barriers to rehabilitation which include factors such as funding, family support and staff availability. Stigma is a barrier to rehabilitation which is not often spoken about.⁶ It is described as “the idea of perceived deviance of an individual’s characteristics from what is typical or the norm in a given context”.⁷ Stigma affects every facet of life of people with disabilities in a negative way.

In this essay, (having gained her consent), I will use my mother’s personal experiences as an example to explore how stigma affects a person’s view of their physical disability and how this can become a barrier to accessing rehabilitation services. I will also discuss ways in which the barrier created by stigma can be overcome and what can be done differently.

The effects of stigma on people with disabilities

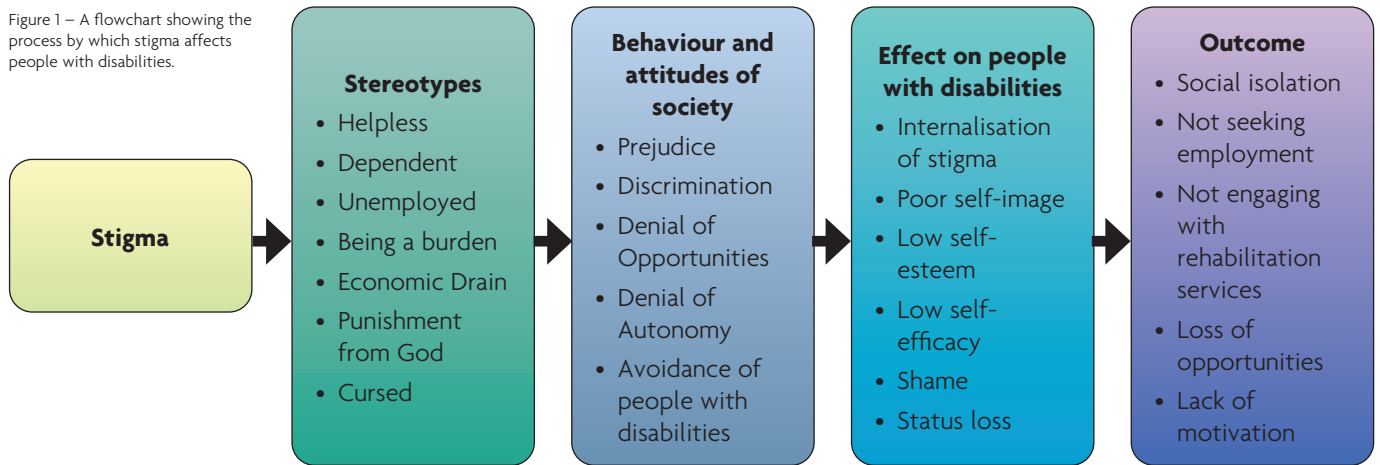
My mother, who is a psychiatrist, was diagnosed with rheumatoid arthritis at the age of 22 when she was a medical student. Despite treatment, her condition got progressively worse and by the age of 41 she could barely walk due to joint damage and deformity. She started to use crutches and eventually a wheelchair for mobility when she turned 44. The biggest hurdle she had to overcome was accepting that she had a disability and needed aids to mobilise as this meant that she had to accept the label of being ‘disabled’. To be disabled was to accept all the negative stereotypes and stigma that went along with it and it took her years to come to terms with this.

Living with a long-term condition or disability often forces a person to adjust to limitations whilst redefining how they see themselves.⁸ Individuals face intense emotions relating to accepting their new lifestyle which may be radically different from the one they had lived or envisioned.⁹ Unfortunately, adaption to long-term conditions and disability can be hindered by having to go through this process within a non-supportive and non-inclusive social climate.

Goffman¹⁰ describes two ways in which stigma can be experienced. A person can be discredited or be discreditable. A discredited person is someone who shows visible signs of attributes that can be stigmatised, for example an amputee. In contrast, a person with attributes that can be hidden is discreditable but has not yet been discredited. Having a hidden disability can lead to people concealing their disability as they fear being discredited and stigmatised. This also poses a dilemma for them as, if they choose not to disclose their disabilities, they may miss out on opportunities to receive support from others.

When people see an individual with a disability, often, due to stigma, all they see is the disability and all other personal attributes are forgotten.¹¹ Stigma can lead to stereotyping, which is the assignment of negative attributes to traits that are perceived as different.¹² Stereotyping can then lead to discrimination and social avoidance.¹³ Disability is associated with a number of stereotypes. As seen in Figure 1, these include being seen as ‘helpless’

Figure 1 – A flowchart showing the process by which stigma affects people with disabilities.



and a 'burden'. When people with disabilities are perceived as 'helpless', they are seen as an economic drain on society, consuming resources but providing nothing in return.¹⁴ There is also fear that disability is a sign of ill omen which is associated with witchcraft or punishment from God.¹⁵

People often generalise from one disability to another, which explains why someone might assume an individual in a wheelchair must also be deaf. They shout at the blind or speak to the companion of an individual with a disability rather than converse directly with the person with the disability.¹⁶ This is something that I have experienced on many occasions with my mother who has a physical disability. When I accompany her to appointments, people will often not acknowledge her and will speak to me instead of her. Even when they speak to her, this is done slowly because they assume she would have difficulty understanding them.

These stereotypes and assumptions associated with disability can lead to discrimination. Figure 1 shows that people with disabilities may be denied employment, housing or other opportunities based on these negative views and misconceptions.¹⁷ Factors such as race and gender can also have an impact on discrimination. Hanna and Rogovsky¹⁸ said that being disabled and black or disabled and female can lead to double the amount of discrimination. My mother is disabled, black and female which means that she faces triple the amount of prejudice and discrimination. These negative views of disability can become internalised by people with disabilities and can affect an individual's thoughts and actions and overall impact on their self-esteem and self-efficacy.¹⁹

How stigma can act as a barrier to rehabilitation

The stigmatisation of disability and chronic illnesses can significantly affect a person's life goals. Sometimes, dealing with the stigma surrounding the condition is more difficult than living with the limitations that may arise due to the disability. Individuals who are

stigmatised may not be motivated to seek treatment or services that could help them as they attempt to avoid negative experiences. This leads to lost or delayed opportunities for treatment and rehabilitation that may improve physical health and quality of life.²⁰ Stigma is such a pervasive problem worldwide that it is considered a public health issue.²⁰ Individuals can feel stigmatised by devices that signal a loss of function as this is a visible sign that can lead them to being discredited by society. This can act as a barrier to rehabilitation.²¹ For example fewer than 25% of adults who needed hearing aids are actually using them, due in part to stigma associated with wearing a hearing aid.²²

When my mother was using crutches, she experienced disability stigma. However, when she started using a wheelchair, the stigma she experienced became amplified and people reacted to her as though she had suffered a bereavement of some sort or that a calamity had befallen her. Some people were ashamed to be seen with her and on one occasion, at a conference, a woman attempted to pray for her by laying hands on her without her permission. Many assumed that she was unemployed and were shocked to find out that she was working full time as a medical doctor.

People with disabilities can also experience stigma from healthcare professionals. This is because healthcare professionals tend to view disability from the 'medical model' (which sees disability as a 'problem of the person' caused directly by trauma, disease or congenital disorders), rather than the 'social model' (which views disability as a problem created by the social environment rather than the individual). In the medical model, management of these 'problems' are focused on a cure or adjustment and behavioural change whereas, with the social model, management is more focused on "the full integration of individuals into society" and therefore is the responsibility of society.²⁰

Parsons²³ talks about how in healthcare, it is recognised that "the task of medicine is to treat and the task of the patient is to get well". Due to this, patients who fail to respond to treatment

can be unpopular with healthcare professionals and therefore treated differently. This has been corroborated by a study conducted by Kaplan²⁴ which showed that rehabilitation counsellors' attitudes to clients varied with how difficult the counsellor perceived the client to be in terms of rehabilitation. The more difficult the counsellor perceived the client to be, the more negative the attitude of the counsellor was towards the client. This can significantly dissuade people with disabilities from accessing services.

How can we overcome this barrier to rehabilitation?

People with disabilities report requesting more healthcare than those without disabilities and yet they have some of the highest unmet needs.¹ As discussed above, stigma has a big part to play in this. Thus, it is imperative that we overcome the negative effects of stigma and remove the barrier it creates in accessing rehabilitation services.

Healthcare professionals need to be aware of the stigma they may be consciously or unconsciously putting on their patients. Attitudes of healthcare professionals can be changed by the integration of "expert" or "experienced" patients into faculty or rehabilitation training courses. These patients, (such as my mother who due to chronic illness has been to multiple clinics and hospital appointments and has an understanding of the patient experience in ways that healthcare professionals cannot), have a perception that is critical to the delivery of patient care and can positively impact on procedures, policies and patient advocacy.²⁵

Even if the stigma from healthcare professionals is addressed, there is still the issue of public stigma. I once attended a dental clinic for a procedure which required sedation and was told that an adult had to accompany me home after the procedure so I went with my mother. Upon our arrival, the Practice Manager assumed my mother was the patient and when we informed her that I was the patient, she asked who was going to accompany me home after the procedure. I told her

that my mother would be. She looked at her and said “she can’t accompany you home because she is in a wheelchair. We are going to have to ask you to cancel the appointment and rebook it for a time when you can come back with someone who is not disabled to accompany you home”.

We were shocked and baffled by her response. My mother uses a motorised wheelchair and drives. The car park was adjacent to the clinic and one of the nurses was going to accompany me to the car after my procedure. We could not understand why she had responded in this way and asked her to justify her comments by showing us their policy regarding this. She was unable to but kept arguing with us. Eventually, we insisted on speaking to the dentist carrying out the procedure who apologised profusely for her behaviour and said that my mother could accompany me home after. This is a clear example of how stigma and assumptions can lead to prejudice and discrimination.

How do we address the issue of public stigma which involves so many people? People’s perceptions of disability can be changed through the media which plays a role in propagating misconceptions of disability and the perception of people who have disabilities, especially in groups of people who have minimal information and interaction with people with disabilities.²⁶ One way this happens is through the language

that the media uses around disability. For instance, the media often uses terminology that reinforces the ‘sick role’ by using phrases such as “suffering from” or “afflicted with”. This gives power to the condition and paints the individual with the disability as a helpless passive victim.²⁷

Using my mother as an example, stating that “she has rheumatoid arthritis” rather than “she is suffering from rheumatoid arthritis”, just as accurately reports the facts and doesn’t impose any extra meaning. Words that empower people with disabilities will result in positive change, not just for the general public but for people with disabilities too as frequently, the negative terminology is internalised and can affect a person’s self-image.²⁷ There is also a need for the media to follow the social model of disability and diversify by integrating people with disabilities into every day media. In a study conducted by Farnall and Smith²⁸ it was concluded that exposure to positive portrayals of people with disabilities, especially in films was associated with more positive opinions towards disability. This has already started with the appearance of Lauren Steadman, (a paratriathlete), on ‘Strictly Come Dancing’ and shows like ‘The Last Leg’ which was created to cover events in the Paralympics in which two of the presenters use prosthetics. If we continue to ‘normalise’ disability in this way in the media, we will be well on our way to reducing disability stigma.

Conclusion

Stigma can have a detrimental effect on the lives of people with disabilities especially when it becomes a barrier to accessing healthcare and rehabilitation services. In a group where secondary complications and co-morbidities are common, it is extremely important to remove any barriers to healthcare.¹ In order to address the problem, it needs to be recognised and addressed by all parties involved. The media has a significant role to play in changing attitudes and perceptions towards disabilities. People with disabilities need to be seen as functional members of the society who can contribute positively and make a lasting impact. The late Professor Stephen Hawking, a theoretical physicist, is an example of a person who despite his disability made great strides in his field.

Finally, more focus needs to be put on what people with disabilities can do rather than what they cannot do. My mother may not be able to walk but she is able to work full time as a medical doctor, treating patients and improving the quality of their lives thereby contributing positively to society. Rehabilitation medicine also has a role to play as it is a speciality where people with disabilities are the majority of the patients and the biopsychosocial model is essential. It should be at the forefront of diminishing the impact of stigma.

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What's in a name? A diagnosis by any other name would be as meet?

It is through the agency of Juliet (who, according to the internal evidence of the play, is not yet fourteen years old) that Shakespeare asks:

What's in a name? that which we call a rose
By any other name would smell as sweet.

(*Romeo and Juliet*, Act II, scene II, lines 47-48).

A recent case highlighted the issue of diagnostic naming, prompting my attempted (lame?) revision of Shakespeare's lines.

A 46-year-old lady with longstanding psoriasis was referred to the neurology clinic by her dermatologist for opinion on recurrent episodes of unilateral facial swelling over the previous three years. These occurred around once a month and lasted for about 24 hours. There were no obvious triggers and episodes were self-limiting. There was no history of facial weakness (confirmed by photos of her face when symptomatic), sensory disturbance or tongue involvement. Previous MR brain imaging was normal. A diagnosis of monosymptomatic Melkersson-Rosenthal syndrome (MRS) was made and the patient reassured that no further neurological investigation was required.

Simultaneously the dermatologist had referred the patient to an allergist. The allergist made a diagnosis of chronic spontaneous angioedema, and checked complement and C1 inhibitor levels which proved normal. The patient was, understandably, confused by the different diagnostic labels.

MRS is defined by the triad of orofacial oedema, recurrent facial palsy and fissured tongue (lingua plicata). Most neurologists will recall MRS amongst the small print causes of recurrent facial nerve palsy but the classical triad is rarely observed, oligosymptomatic and monosymptomatic forms being more common.¹ Facial oedema is the most common initial finding and is an acknowledged mimic of hereditary or acquired angioedema. A possible association of MRS and psoriasis has been described.² Allergic diseases (atopic eczema, allergic rhinitis) have been observed concurrently with MRS.³

Eponyms may sometimes be memorable,

particularly if the name(s) involved seem(s) exotic; MRS may fall into this category, despite its rarity (I believe I have only diagnosed it once before in 20 years as a Consultant). Eponyms may prompt those with an interest in history to investigate the originators, if indeed they were the first to describe the disorder. It is possible that neither Ernst Melkersson (1928)⁴ nor Curt Rosenthal (1931)⁵ were the first to report "their" condition.⁶

Naming may be conceptualised as a form of cross-modal non-contextual paired associate learning, a process which may be challenging for both learning and retention. How often do patients attending the cognitive clinic complain of difficulty remembering peoples' names? Eponyms may have a certain economy of expression, but risk implying uniformity where there may in fact be heterogeneity, for example at the clinical, investigational, pathological or genetic level ("Pick's disease" might be cited as a good example of this). Moreover, eponyms convey no information on pathogenesis or aetiology, whether defined or suspected, of the disease they denote. The case may therefore be made that this is a situation in which the more descriptive, if prosaic, nomenclature is to be preferred.

Other arguments in favour of abandoning eponyms have been made, for example in cases of misnaming, misattribution, and misuse, and for lacking accuracy.⁷ The ethical imperative to expunge from eponymic recognition those involved in Nazi activities is well recognised.^{7,8} However, others favour retention,⁹ and it seems that de facto eponymous labelling will persist, with the potential to confuse patients.

If we agree with Cicero's claim, in his *Tusculan Disputations*, that the "imposition of names on things is the highest part of wisdom,"¹⁰ then care is needed in this exercise since it is more than simply an arid exercise in semantics. Overall I am sympathetic to the position favoured by Woywodt and Matteson,⁷ that medical eponyms should be abandoned in favour of a more descriptive nomenclature. A potential implication of this approach is that nomenclature should be provisional, and hence flexible in the face of new understandings of disease processes.

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How the British Neuroscience Association (BNA) is creating an exciting and sustainable future for 21st century neuroscience

By Dr Anne Cooke, Chief Executive, BNA



In November 2019, the BNA officially launched its 'Credibility in Neuroscience' programme at an event at the Houses of Parliament. Along with keynote addresses from Professor Dorothy Bishop and Lord Robert Winston, the main focus of the event was the release of the BNA's 'Credibility in Neuroscience' Manifesto with its vision for why and how we must urgently change the research culture within neuroscience.

An increase in irreproducible research

It's not over-dramatic to state that we're at a crucial turning point in research across the biosciences. It's become clear we don't always reward the best science – that's science that lays equal value on both positive and negative outcomes (i.e. findings which reject and those which accept the null hypothesis) and that recognises the importance of replication. Instead, there's a huge pressure to publish as much research as quickly as possible, to make findings newsworthy, and to favour certain kinds of research outcomes over others. Increasingly, researchers are being influenced to produce the 'right' result, which in turn has meant a growth in irreproducible research. And where research is irreproducible or non-replicable, we risk:

- Stalling scientific progress and understanding
- Jeopardising the translation of research to real-world applications
- Wasting time and money
- Hyped expectations
- Losing public trust in scientific findings

It's a reality which most people will agree is detrimental to science, as well as society.

As the UK's largest professional neuroscience organisation, at the BNA we recognise our responsibility to address this threat in neuroscience. Which is what has led to the launch of our 'Credibility in Neuroscience' programme – one of our most important, high-profile programmes to date, championing the principles of open science, replicability, reliability and reproducibility in research.

Supported by the Gatsby Foundation, the backbone of 'Credibility in Neuroscience' is our manifesto for change. Here, we've set out our clear vision to achieve our aim to support and promote the credibility of neuroscience.

Our vision

To ensure that neuroscience research is as robust, reliable, replicable, and reproducible as possible; in short, to ensure the credibility of neuroscience.

We've also outlined three core commitments that will ensure we can deliver and progress our vision as a scientific community.

Our commitments

- Supporting a shift in research culture that's welcomed and desired by the whole neuroscience community.
- Equipping all neuroscientists – regardless of career stage, location, research topic or specialist technique – with the skills, knowledge, tools and processes they need to carry out neuroscience research which is as credible as possible.
- Changing the landscape in which neuroscientists operate, so that the influences which drive neuroscience research also drive the most credible research.

We believe strongly as an organisation that to ensure a sustainable future for 21st century neuroscience research, we must ensure the credibility of research. We must keep challenging aspects of today's research environment. We must ensure everyone, at whatever stage or nature of their career, has access to support, guidance, and reassurance so they can embrace and implement the necessary changes that will benefit the whole community.

So, what is the BNA doing on the ground to promote credibility?

It's important to point out this isn't a campaign only of words, but of actions. From sharing best practice and creating a space for vigorous discussion and debate, to equipping researchers with the right tools and incentives to try something new, this is a programme of progress and development.

On the one hand, we're committed to raising awareness, facilitating discussion and helping all neuroscientists stay informed about credibility. On the other, we'll be driving through practical changes, providing the knowledge and tools required to adopt credible research processes.

Informed and supported by our Credibility Advisory Board of leading neuroscientists and open science experts, we're launching an ongoing range of activities, events and practical guides. From running a UK-wide 'Credibility in Neuroscience' roadshow with seminars and workshops, bringing neuroscientists together to discuss and implement credibility, to credibility 'toolkits' consisting of practical resources and short guides developed by our team of experts.

Working together as one community

We're committed to connecting and uniting everyone, from journal publishers and societies, to universities, funders and the general public, within one neuroscience community. It's why our 'Credibility in Neuroscience' programme forms a fundamental part of what we're doing to support and champion our members. Because bringing everyone together to be part of UK-wide events, news, networks, and support is vital to making changes and new practices universal and accessible to all.

Only by ensuring everyone has the support to be 'InCredible' will we truly advance and secure the future of neuroscience.

More information can be found on the 'Credibility in Neuroscience' website: www.bnacredibility.org.uk



Take a step towards InCredibility today

If you are a neurologist or other healthcare professional...be InCredible by sharing your knowledge of preregistration, and by checking out the AllTrials campaign.

The clinical research community is already well-versed in preregistration, much more so than academic researchers. Take the chance to share your knowledge of preregistration with colleagues in academia. Also combat the invisibility of negative results by checking out the AllTrials campaign at alltrials.net.

If you are a researcher in neuroscience or another bioscience...be InCredible by changing how you publish.

Publish null results, preregistering research or submitting a Registered Report where appropriate, and using CRediT wherever possible. If you lead a lab then make sure your team are aware of new approaches in publishing.

If you work in industry or the commercial sector...be InCredible by sharing your knowledge.

Talk to an academic friend or colleague about the issues they are facing, share your knowledge with them, and take the chance to discuss how credibility is important to translate research into real-world applications.

If you are a publisher or editor of a scientific journal...be InCredible by having journal policies which support replicability of research.

Accept replication studies and null results in your journal, and ensure methods sections are comprehensive enough to allow the published work to be replicated.

If you fund neuroscience research...be InCredible by supporting the sector to help make science open.

Talk to your grant holders about what they are doing to contribute to this cultural change and open science, ask them what they would like to see change and how the funding you offer could support this.

If you work in the media...be InCredible by including caveats and limitations

Support and highlight negative results, including caveats or limitations when writing science or health news. Report what a study doesn't show as well as what it might, ensuring column inches for the important detail as much as the headline grabbers.

If you want to be a part of the change...be InCredible by joining the BNA.

Join the voices of neuroscience and be the change you want to see.



We are your voice

With high profile campaigns like 'Credibility in Neuroscience' the BNA is ensuring we give a voice to everyone interested in the brain and nervous system, from researchers and clinical scientists to students and the general public.

Be part of a vibrant, forward-thinking community, for the price of one coffee a week (or much less!), and benefit from:

- Up-to-date news about events, lobbying and networking opportunities
- Free membership of the Federation of European Neuroscience Societies (FENS) and the International Brain Research Organisation (IBRO)
- Free or reduced registration rates for all BNA events
- The BNA Bulletin magazine
- Reduced APC charges for the BNA journal 'Brain and Neuroscience Advances'
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Vladimir Mikhaylovich Bekhterev (1857-1927)

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Among many Russian neuroscientists (who included Vladimir Betz, Konstantin Tretiakoff, and Alexander Luria) was Vladimir Mikhaylovich Bekhterev, (1857-1927) (Figure 1). Neurologist, morphologist and experimental psychologist, he was a most industrious, inventive and inexhaustible physician. Born in Sorali, a remote village between the Volga and the foothills of the Ural mountains, he became a distinguished neurophysiologist and psychiatrist who advanced the functional anatomy of the brain, experimental psychology, clinical neurology, and conditioned reflexes.¹ Paradoxically, Bekhterev's disease (ankylosing spondylitis) is better known than his neurological works where he described: the acromial reflex, Bekhterev's superior vestibular nucleus, labyrinthine nystagmus, the pectoralis reflex, a paradoxical reflex: pupillary dilatation to light, and several arcane reflexes in the limbs.

As a child Bekhterev spent much of his time reading the natural sciences. Aged 16, he enrolled at the Military Medical Academy in St Petersburg, and graduated in medicine in 1878. Already curious about the workings of the brain, from 1884-5 he secured a travelling scholarship to study under Flechsig in Leipzig and there described the superior vestibular nucleus—another Bekhterev-bearing eponym. When he visited Meynert, Westphal, Wundt, and Charcot, stimulated by their work he widened his enquiries. In his 1928 autobiography, he explained his curiosity about the brain:

"That time the old expression *'textura obscura, functiones obscurissimae* [an obscure texture, and the most obscure functions]' could be fully applied to our knowledge of the brain. My desire to light this darkness was the reason to study the brain structure and functioning".²

When in 1885 he returned to Russia he had already secured a considerable reputation. Aged only 28 he became Professor of Psychiatry at the University of Kazan, where

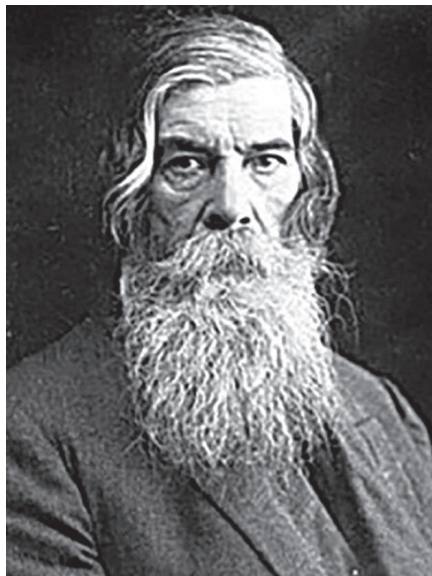


Figure 1

he established the first laboratory of experimental psychology in Russia. In 1893, having published more than a hundred papers, he became Professor of Psychiatry at the Military Medical Academy in St. Petersburg, continuing both neuropathology and neuropsychology studies.³ As well as his discovery of the superior vestibular nucleus, succeeding Freud's work he described the central tegmental tract, the connections of the olivary nucleus and cerebellar peduncles.⁴

The second edition of his *Conduction Paths in the Spinal Cord and Brain* 1896 was the most comprehensive anatomical description of the time. So famous had Bekhterev become that the German anatomist Friedrich Kusch, said,

There are only two persons who know the anatomy of the brain perfectly—God and Bekhterev.

He founded the first Russian journal on nervous disease, *Neurologicheskyy Vestnik* in 1896 and set up the Leningrad Psychoneurological Institute in 1907. Here he furthered his investigation of the relationship between human brain physiology and behaviour. In politically troubled times he was forced him to resign his Chair in 1913; it was restored following the Russian Revolution of 1917 when he headed the department of psychology and reflexology at the University of Petrograd in St. Petersburg.

Bekhterev wrote ceaselessly with extraordinary endurance: he was said to need only five hours of sleep. The result over 50 years was more than 600 scientific papers and 10 books. His book on reflexology (1921) was translated into German and English.⁵ Among his more significant writings are *Conduction Paths in the Brain and Spinal Cord* (1882; 2nd ed., 1896)

and *Objective Psychology* (1907). His lasting legacy was on brain morphology, function, conditioned reflexes and several original clinical papers.

In the same decade as Strümpell and Pierre Marie,⁶ Bekhterev in 1893 described ankylosing spondylitis: known both as Bekhterev's disease, and Marie-Strümpell disease,⁷ observing the rigidity and curvature of the spine, and the

'Ankylosing inflammation of the spine and the large extremity joints.'

But these accounts were long after the convincing 17th century instance in a skeleton discovered in a French graveyard reported by Bernard Connor to the Royal Society:

Vertebrae and ribs "were so straightly and intimately joined, their *Ligaments* perfectly *Bony*, and their *Articulations* so effaced, that they really made but one uniform continuous Bone; so that it was as easy to break one of the *Vertebrae* into two, as to disjoint or separate it from the other *Vertebrae*, or the *Ribs*".⁸

Benjamin Brodie (1783-1862) also had described a probable case observed in 1841, who complained of pain and stiffness in the dorsal and lumbar spine, buttocks, and knee joint, plus iritis.⁹

In his studies of conditioned reflexes he competed with Ivan Pavlov (1849-1936) who won the Nobel Prize in Physiology or Medicine in 1904. Bekhterev independently developed his own theory though it differed little from Pavlov's notions. After their early years of friendship there developed considerable personal acrimony and disagreement. He insisted on a purely objective approach to the study of behaviour. He was convinced that complex behaviours could be explained through the study of reflexes, a notion that influenced the growing *behaviourism* that surfaced in America.

Bekhterev married twice, and had six children with his first wife Natalya Bazilevskaya. While she was living abroad after the Russian revolution, Bekhterev met the much younger Berta Gurdzhi. After Natalya died in 1926, he married Gurdzhi at the age of 70. The circumstances of his sudden, unexpected death in 1927 are much debated. He was summoned to the Kremlin to perform a medical examination on Stalin and reported: "I examined a paranoid with the dry hand". This comment, reaching Stalin (who had a left arm deformity after childhood injury and infection), angered him, as he would not admit rumours about his mental state. Within a day or two, on Christmas eve 1927, Bekhterev was dead. The day before his death he had chaired a congress of Soviet

neurologists in Moscow. Many believed that the Russian authorities poisoned him,¹⁰ though there was 'no proof'.¹¹ However, the Kremlin authorities insisted on cremation¹¹ and, his name and all of his works were erased from Soviet literature until Stalin's death in 1953.¹² The most plausible explanation of Stalin's late paranoia is 'the dimming of a superior intellect and the unleashing of a paranoid personality by a multi-infarct state'.¹³

Bekhterev was a dynamic, gifted man who explored new fields in psychology and brain morphology in a career marked by vagaries and incident. Eventually, a sculpture was erected in the Volkovo cemetery at St. Petersburg in the 1970s and a 5-ruble stamp in 2007 commemorates him (Figure 2).



Figure 2.

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Deep Brain Stimulation: Techniques and Practices

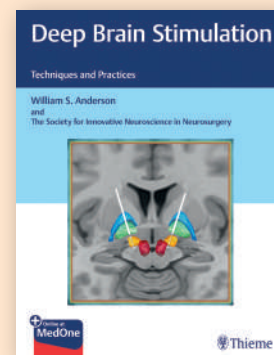
Deep brain stimulation (DBS) is an area of practice within Neurology perhaps analogous to DMT for multiple sclerosis, and selection of epilepsy patient for surgery. That is, a subject with which a general neurologist might be familiar only in a very general sense but nonetheless see patients for whom the treatment is exactly the right option to pursue, maybe sooner rather than later. While sitting in a colleague subspecialist clinic might appeal as a means of increasing familiarity, it is hardly realistic in view of the demand on our time.

This multi-author volume with contributors from The Society for Innovative Neuroscience is edited by William Anderson, and has the same level of polish as all the Thieme neurosurgical textbooks. It is concise and has a reasonable price tag, and is intended primarily for practising neurosurgeons as a quick reference. For Movement Disorders neurologists contributing directly to DBS services, it might also be used as a basic reference text. For most of us, it is best considered as a broad-ranging, accessible and authoritative update on DBS, obviously better suited to most of our diaries than arranging to sit in on a suitable colleague's clinic.

If we consider the volume's potential readership geographically, rather than by specialism, its North American readers are offered some pointers on the practicalities of setting up a DBS neurosurgery 'business' in the last chapter. It is also noticeable that some, but not all, of the individual chapters' authors adopt the style of referring to authorities of past and present by title, i.e. Dr Smith rather than just 'Smith' having done or written such-and-such. I think that may be a North American practice. That quaintness and slight inconsistency aside, the chapters read very well, and the volume as whole is very coherent.

I was about make note of an omission for this review, that the role of DBS in status dystonicus was not mentioned. But, while it is not covered in the Dystonia chapter, I found that it was described in the chapter on DBS in Paediatric practice.

In the historical introduction, I was interested to hear that Horsley in the early 1900s treated a patient suffering involuntary movement of one hemi-body, by contralateral resection of the motor cortices, i.e through causing paralysis. By the 1930s, however, lesions of the basal ganglia were deployed to relieve movement disorder



Edited by: William S Anderson

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Reviewed by:

Rhys Davies, Consultant Neurologist, Liverpool.

symptoms, without necessarily causing weakness, although the pioneers of this approach had to contend with criticism from those who held to the prevailing wisdom that any surgery to the basal ganglia would lead to coma. While such reservations seem conceptually bizarre to us, of course, it's a mere hair's breadth from some points in the basal ganglia to parts of the brainstem where damage would indeed switch off the lights.

As to the sequence of chapters, they range from sections describing DBS treatment in specific conditions, from PD through other movement disorders, to psychiatric conditions and epilepsy. The ordering seems reasonable, but it would have felt more natural for me if tic disorder has been grouped with the movement disorders rather than after the psychiatric ones. A factual tidbit I won't forget, not least because I should have been able to work it out for myself, is that the internal segment of the globus pallidus is a bigger thing than the subthalamic nucleus and, therefore, technically easier as surgical target. But of course, there are other interesting, practical insights.

Holistically, the volume's ethos is very much pro-DBS, which is obviously fair enough for the business-minded DBS neurosurgeon in jurisdictions other than ours! I must say, I think that ethos is also appropriate for clinicians on the front line of managing a whole range of 'DBS-able' diagnoses, be they neurologists, other physicians or psychiatrists. On the whole, I think we should be more alert to the suitability and availability of DBS for our patients, and this volume contributes usefully to that.

The Comorbidities of Epilepsy

The Comorbidities of Epilepsy is a sweeping view of the myriad links between epilepsy, and multiple aspects of health. Edited by Marco Mula, it has the support of the International League Against Epilepsy (ILAE), with a foreword from the president. The chapter authors are international, predominantly from Europe and North America, all highly regarded within their fields.

This book is clearly the result of tireless excavation and subsequent pulling together of the existing evidence base for many disparate areas relating to epilepsy. It has 19 chapters, addressing the hinterland of areas such as obesity, cancer, bone density as well as more familiarly trodden areas such as psychosis and depression in patients with epilepsy.

Many chapters immerse us in the historical basis of our current thinking, and methodically bring us up to date, where the evidence base is often weak. Using case reports to provide a balanced view on each subject, it provides rigour and depth of knowledge about areas which are often skimmed over in clinical practice, if broached at all.

Before reading, the interaction between epilepsy/anti epileptic drugs and cancer or inflammatory bowel disease was not something I have previously considered. The exhilarating feeling of seeing familiar areas, obesity, cardiovascular disease, bone health, and cancer, through a refreshing new lens, when related to epilepsy, recurred throughout my reading of this book. It provided pause for reflection in every chapter, and a paradigm shift occurred within me.

Who is it for?

The myriad ripple effects of Epilepsy and its management are explored in detail, and the subjects are of relevance to all professionals who care for patients with epilepsy, including specialist nurses and general physicians.

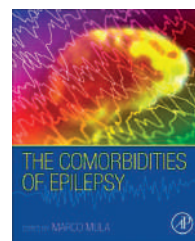
Limitations

This is not a companion book. It could not be carried around easily, and its 'dippability' factor (can I dip in for 5 minutes here and there and easily access information?) is moderate. The text is dense with sparse illustrations or diagrams, although the images provided are beautifully presented. The text is well formatted, in a way that I found easy to read, and to follow. End of chapter summaries with key highlights would have enhanced my experience of this.

The weakness of any academic textbook, is the fear that the evidence can date quickly. Many clinicians prefer to go first to recent reviews in clinical journals when updating knowledge (especially as there is a lack of shelf space). This is where the book comes into it's own. It is unique in its perspective, enriched by evidence, each chapter is a detailed review of where we are at present. I sense that many of the areas are not rapidly evolving and this book will remain a good foundation for further reading for many years to come.

In summary, this book was a joy to read, and provided new knowledge, as well as enhancement of existing knowledge when considering psychosis in epilepsy. It widens the view of how the patient with epilepsy is affected by their diagnosis, and how we can acknowledge that and help in a comprehensive way. Having read it, I feel empowered to 'add value' to my consultations with patients with epilepsy by facing these additional areas. By diagnosing sexual function and cognition, and to wander away from the safely trodden script focused on seizures alone.

Having read it in detail over the last few months, will I continually return to it? Time will tell. I conclude that I will return to it time and time again, for teaching preparation and for enhancement of my clinical consultations.



Edited by: Marco Mula
Published by: Academic Press, Elsevier 2019

Price: £98.95

Pages: 413

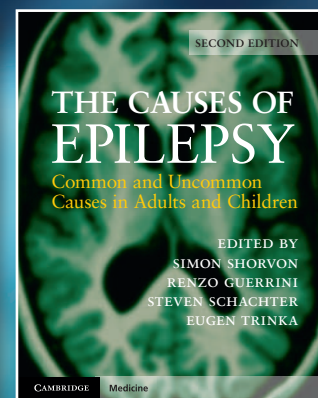
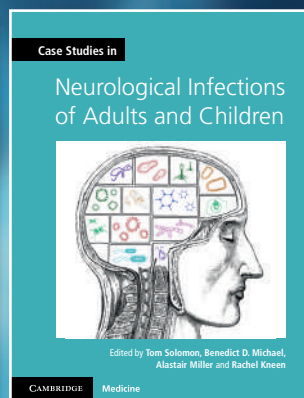
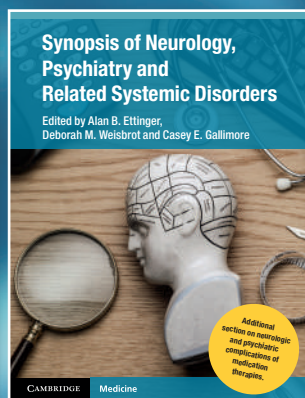
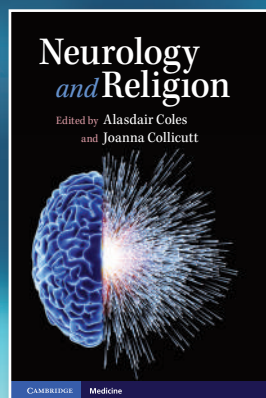
ISBN: 9780128186206

Reviewed by: Dr Ann Donnelly.
This book shares a title with the one-day course, which she has also reviewed on the opposite page.

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Conference details: 14-15 October 2019, University of Warwick, UK. **Report by:** Andrew Bateman, Reader, School of Health & Social Care, University of Essex, Fiona Rowe Professor in Orthoptics and Health Services Research and President of the SRR. **Conflict of interest statement:** None declared.

On 14th and 15th October 2019, the Society for Research in Rehabilitation (SRR) and the British Society of Rehabilitation Medicine (BSRM) held their joint scientific meeting at the University of Warwick.

This was a very well attended meeting with representation from multiple disciplines within the rehabilitation community.

The meeting was a huge success with excellent feedback from the delegates. There were a number of special mentions to demonstrate the popularity of the fast forward poster sessions. Over 90% of delegates who provided feedback found the meeting very effective or effective for their professional development. This is a great accomplishment and indicated that the target of aiming the content for the audience of mixed rehabilitation professionals/researchers, was achieved.

The content across the sessions on both days largely related to two themes: complex rehabilitation problems including sleep, spasticity and ethics, and the elderly and rehabilitation, covering the topics of towards

independent living, amputee rehabilitation, hip replacement and neurological injury.

Further sessions included cardiac rehabilitation and goal setting in rehabilitation in addition to a number of free paper sessions with excellent individual research papers delivered by the presenters.

Dr Charlie Whiffen, an intensive care nurse from the University of Derby, spoke about her work visiting patients and their families after their stay in an acute neurosurgical ward. She visited nine families at one, three and twelve months after their stay in hospital and developed a detailed narrative understanding of the turbulent times that families experience after such a traumatic experience.

Dr Sheeba Rosewilliam, a physiotherapy lecturer from Birmingham, gave an erudite presentation challenging the current use of goal setting in rehabilitation, proposing alternatives from behaviour change techniques, motivational interventions and shared decision-making approaches.

There was an engaging presentation by Emeritus Professor Derick Wade for the

Bipin Bhakta memorial lecture, entitled 'Rehabilitation will only survive in the UK if politicians, the public, and other healthcare professionals know what it is. How should we fight for its survival?'

The conference concluded with a lecture by the local host Prof Di Playford who encouraged the community to explore opportunities for more playfulness in the rehabilitation setting.

An additional key element to the success of the meeting was the inclusion of a pre-conference training day for medical students – an important move to promote the advancement of rehabilitation.

The SRR and BSRM are already well underway in the organisation of the 2020 joint scientific meeting. Watch our websites and twitter feeds for announcements on venue and dates for this great meeting.

Web: www.srr.org.uk www.bsrm.org.uk
Twitter: SRR – @rehabresearchuk
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The Comorbidities of Epilepsy

Conference details: 5 July 2019, St Georges Hospital, London, UK. **Report by:** Dr Ann Donnelly, Locum Consultant Neurologist for Royal Free Neurorehabilitation Centre and Co Editor in Chief, ACNR. **Conflict of interest statement:** None declared.

This one day course, run by Dr Marco Mula and Dr Mahinda Yogarajah is in its second year. It provides a confident and useful view into commonly encountered difficulties such as headache and pregnancy, as well as less prominent areas like sexual dysfunction and sleep.

The course had three sessions. The presentations were succinct, entertaining and provided us with a glimpse of the future while reminding us of the giants of medicine upon whose shoulders we stand.

The attendees were a predominantly from a neurology background. Although there were trainees, consultants, with some allied health professionals linked to epilepsy the content was pitched at a level beyond specialty training.

There were interactive question sessions, which involved the whole group.

The lectures provided useful updates on current guidance, highlighting where evidence may be lacking and how we may best approach areas which have great importance to our patients, but have not received much attention from the research community.

In a busy clinic, it can be tempting to focus only on seizure frequency and medication, while ignoring the less evidence supported areas of sexual function, sleep and mood. To a person with epilepsy, any of these can radically affect quality of life, and this course allowed us to view the existing practice, with a balanced view of the evidence. There were practical views throughout and case reports brought relevance to each area.

The course began with an update on the recent pregnancy guidelines from John Craig, followed by a look at headache and bone health. Fergus Rugg Gunn offered a beautifully illustrated view on the history of ictal and cardiac risk. The complex interaction between epilepsy/anti epileptic drug treatment and increased cardiovascular risk factors as well as the increased risk of cardiac dysrhythmias is significant, reminding us of the NICE guidance to do an ECG on all patients with epilepsy.

Dr Yogarajah covered sexual dysfunction and epilepsy. This is an under explored area, and appears to be more common in patients with epilepsy, particularly temporal lobe epilepsy. Anti epileptic medications can

also affect sexual function, and the known effects were reviewed.

Arjun Sen covered the network disorders of Alzheimer's and Epilepsy and discussed how these may be linked and how best to consider the choice of anti epileptic medication.

The afternoon session provided a practical approach to sleep, and Dr Mula's experienced overview of depression and psychosis, with interactive questioning, and a discussion about the best approach to grey areas.

This course can provide the neurologist, or general physician, with confidence to approach the multiple ways a life is affected by epilepsy. By at least helping us to define the problem, and by offering practical considerations we can provide more comprehensive support to our patients.

This one day course is informative, and is unique in the approach to a common neurological condition. It has relevance to all general neurologists, irrespective of training level, as well as clinical nurse specialists. It is useful at consultant level and beyond, pitched more for the neurologist who may have a focus other than epilepsy.

UKABIF 11th Annual Conference 2019 – Driving change in neurorehabilitation

Conference details: 11 November 2019, London, UK. **Report by:** Louise Blakeborough MSc, on behalf of UKABIF. **Conflict of interest statement:** None declared.

Dr Andrew Bateman, UKABIF Chair, and James Piercy, UKABIF Trustee and Science communicator, welcomed over 250 delegates to the organisation's 11th Annual Conference, held in November at London's Royal Society of Medicine. The words 'time for change' echoed throughout the day as the conference programme discussed the workstreams flowing from the All-Party Parliamentary Group (APPG) on Acquired Brain Injury (ABI) report 'Acquired Brain Injury and Neurorehabilitation: Time for Change' published in September 2018.

Opening the conference Professor David Menon, Head, Division of Anaesthesia, University of Cambridge and Honorary Consultant, Neurosciences Critical Care Unit, Addenbrooke's Hospital, Cambridge said: "Neurotrauma is, and will remain, the biggest cause of neurodisability, but it continues to be under-resourced and presents many challenges for societal care. Being alive following a brain injury is not enough – we need to know the extent of the injury and the predictable outcomes." There is a burden of mortality over a 10-12 year period post-injury due to the chronic sequelae, and also infection susceptibility, which results from immune response modulation. This burden reinforces the need for long-term care. Professor Menon discussed the key issues in the 'Time for Change' report and said: "UKABIF and the APPG on ABI have made a huge impact in raising awareness of ABI and driving change. We need to continue to ensure individuals with life-long disability receive the long-term care and support they require."

A head-on collision in France in 1998 left the second speaker of the day, Dr Raymond Lynch, with debilitating brain and spinal injuries. Through determination and the help of a neuropsychologist he turned his life around and, with the support of his employer Proctor and Gamble (P&G), now consults with the UK Government and London-area hospitals on brain injury. Dr Lynch discussed the 'Return To Work' Toolkit that he has developed for P&G employees worldwide with brain injury, their managers, peers and families.

Unfortunately due to the General Election the MPs Chris Bryant, Liz Twist and Sir John Hayes, who are driving the APPG on ABI were unable to attend the conference. In their place Dr Bateman discussed the aspirations of the APPG and highlighted the considerable amount of work being done as a direct result of UKABIF and the APPG engagement.

Mental health and neurorehabilitation are traditionally segregated, but as Dr Mike



Dr Andrew Bateman, Chair of UKABIF chaired the 11th Annual Conference.

Dilley, Consultant Neuropsychiatrist in Neurorehabilitation, Brain and Mind said: "Mental health needs to be integrated in to neurosciences and neurorehabilitation." Neurological conditions and psychological problems are inextricably linked; studies have shown that there is an increased mortality after brain injury and mental health problems worsen life expectancy. Accessing mental services as part of a continuous chain of rehabilitation can be extremely challenging and early access is an essential part of recovery. "The system urgently needs to be integrated," concluded Dr Dilley.

The focus on change was reiterated by Trevor Sterling, Partner at Moore Blatch because there has been no review of injury cost recovery since the Major Trauma Centres were introduced. Current legislation is outdated and the extent of the shortfall in injury costs to the NHS is unknown, resulting in the NHS being underfunded as a consequence. Mr Sterling said: "We urgently need new legislation, and as a minimum, a review of the existing legislation which could facilitate increased funding for neurorehabilitation."

The Silverlining Brain Injury Charity, founded in 2006, shared the experiences of 23 of its members when they recently went to Namibia, Africa. The film of the group's experience was a powerful reminder of the need and importance to invigorate, motivate, nurture and enable individuals with brain injury.

Drs Emily Bennett and Emily Talbot, Consultant Clinical Psychologists in Paediatric Neuropsychology, Nottingham Children's Hospital, outlined the importance of communication, education, monitoring, and adapting in order to support children and

young people with an ABI in the education system. Education is one of the work streams in the Time for Change report, with emphasis on the need to train teaching professionals about ABI, and facilitate change for children and young people with ABI.

Professor Diane Playford, Professor of Neurological Rehabilitation, University of Warwick and Consultant in Rehabilitation Medicine, South Warwickshire Foundation Trust and Ines Kander PhD student at Warwick University, highlighted once again the need to change the community rehabilitation system which is, at best ineffective, and at worst unavailable. Professor Playford said: "Commissioning services for neurorehabilitation is complex with Level 1 commissioned by NHS England, Level 2 by the Clinical Commissioning Groups and no clear pathway for Level 3. Health professionals work in silos and consequently individuals with ABI fall between the cracks." Professor Playford reiterated the lack of Rehabilitation Medicine Consultants, Multidisciplinary Team members, poor information provision and inadequate long-term funding. "We constantly underestimate the number of individuals requiring neurorehabilitation in the community, and their inability to navigate the system. People need access to multiple services, neurorehabilitation for a longer time period and a Linkworker to facilitate progress through the pathway. We need to do it smarter and differently" concluded Professor Playford.

Several awards were presented during the conference. Two new UKABIF Chairs' Merit Awards were presented to Susan Pattinson, Physiotherapist at STP Therapy Services and Hannah Farrell, Clinical Specialist Physiotherapist in Neuro-Traumatology, Queen Elizabeth Hospital Birmingham, in recognition for their work in making change happen in neurorehabilitation. The Stephen McAleese Award for Inspiration went to Dr Melanie George, Consultant Clinical Neuropsychologist, Kent and Medway NHS and Social Care Partnership Trust. The new Mike Barnes Innovation Award, run in collaboration with the National Institute for Health Research, went to Dr Penny Trayner, Paediatric Clinical Neuropsychologist at Clinical Neuropsychology Services Ltd. This year delegates were able to vote for the Poster Award which went to Charlie Flint of Chroma.

UKABIF would like to thank the conference sponsors Cygnet Health Care, Irwin Mitchell solicitors, Leigh Day, Manton Heights ABI Unit, Sintons Law and Stroke Active, the many companies that exhibited and the excellent poster presentations.



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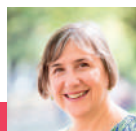
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UCL

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2/3 April 2020

The course is designed for consultants and senior trainees in neurology and other neuroscience specialties, from the UK, Europe and worldwide, and aims to provide a practical update on the hospital management of neurological diseases. The focus of the course is on everyday neurological practice which will include lectures and a CPC. The course will be didactic, but also entertaining and informative, and will be accompanied by a detailed course book. The course takes place in the JZ Young Lecture Theatre, UCL Anatomy Building, with catering in the Jeremy Bentham. South Cloisters UCL Wilkins Building, WC1E 6BT.

- Features:**
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 - A course book providing speaker profiles

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Thursday and Friday Course fees:

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<http://www.ucl.ac.uk/ion/education/courses/other/neurology>



Wednesday 1st April

Pre-Course Symposium: Preparing for the Speciality Certificate Exam

Course Fee: £70 for half day course

29th Alzheimer Europe Conference

– “Making valuable connections” #29AEC

Conference details: 23-25 October 2019, The Hague, Netherlands. **Edited by:** Kate Boor Ellis, Communications Officer, Alzheimer Europe.

Conflict of interest statement: None declared.

The 29th Alzheimer Europe Conference, “Making valuable connections” was held in The Hague in October. A record 954 participants travelled to the conference from 46 countries.

Iva Holmerová, Chairperson of Alzheimer Europe, opened the conference, extending a special welcome to the 36 people with dementia who were among the delegates, as well as their supporters. She noted that public awareness of dementia has increased in recent years, and that the number of national dementia strategies is growing across Europe, as is the number of dementia-friendly initiatives in many countries. She was also pleased to share that policy-makers have begun to acknowledge that, due to the complex nature of dementia, better coordinated research is needed, coupled with increased funding. All of this needs to happen in the modern, fast-paced and sometimes confusing context in which we all live. As a final point, she highlighted the importance of better awareness of dementia, not only for the sake of people with dementia and their relatives, but for the sake of society as a whole, which must find ways to overcome hurdles and to fill the gaps in its understanding.

Myrra Vernooij-Dassen spoke on behalf of INTERDEM (Early detection and timely INTERvention in DEMentia). She emphasised the importance of taking responsibility to move the field forward, mentioning three ways in which this could be done: Firstly, more individualised interventions need to be developed, based on a better understanding of both the variety of ways in which people may be affected by dementia and of the mechanisms of change underlying effective interventions. These interventions include cognitive, functional and social interventions and can use adapted new technologies. Secondly, models of co-production in dementia research and in implementation of research findings could also be developed. Finally, the next generation of dementia care researchers could be stimulated, educated and mentored.

Helen Rochford-Brennan addressed delegates from her perspective as a person living with dementia. She highlighted the value of the voice of people living with dementia, in particular drawing attention to the benefits of patient and public involvement (PPI). She also stressed that more communication and knowledge-sharing in the research community is vital, to avoid “reinventing the wheel”. Researchers need to branch out beyond their current pool of contacts, to move things forward, she said. “We know Europe is becoming more diverse, but researchers need



to seek out those new voices and not take the easy option by asking the same people over and over again.”

The second day of the conference focused on diagnosis, post-diagnostic support, technology and e-health.

Gerjoke Wilmink (Netherlands), led the first plenary session with a presentation on “Improving the diagnosis, post-diagnostic support, care and inclusion of people with dementia: the findings of the 2nd European Joint Action on Dementia”, given by Geoff Huggins, the Director of the NES Digital Service. The findings of the Joint Action that he shared, were: There is already knowledge in place about how to offer good quality care for people living with dementia, so the challenge for health care systems is not about knowing what to do, but rather it is about implementation and change; The Joint Action demonstrates that implementing the same or a similar evidence base in different environments will get different outcomes; Properly involving people living with dementia and their families is always of value and leads to outcomes more in line with their wishes; and finally, local leadership really matters. The EU Joint Action “Act on Dementia” began in March 2016 and ends this year. Its main aim is to promote collaborative actions among Member States to improve the lives of people with dementia and their carers.

Wiesje van der Flier, head of clinical research at the Alzheimer Center Amsterdam at Amsterdam UMC, presented a session entitled, “Research leading to better diagnosis and care in memory clinics – findings from the ABIDE project”. The Alzheimer’s Biomarkers In Daily practiceE (ABIDE) project found that, while advances in early and accurate diagnosis of Alzheimer’s disease are among the largest research successes in the field, they also come with new challenges – for example,

the advance of diagnostic tests means there are more choices to be made. Wiesje van der Flier shared that an audiotape study, completed by the ABIDE researchers, revealed that shared decision-making in the context of dementia diagnosis is not yet common practice. In response to this, the project has developed a simple list of topics to discuss during the diagnostic process and a “conversation-starter” for the diagnostic encounter, both of which aim to empower patients and carers, and to promote shared decision-making. Finally, she said that, through the use of “big data”, the project developed statistical models that can be used to enhance interpretation of diagnostic test results (e.g. MRI, CSF biomarkers). This will support clinicians to provide personalised diagnostic care and to explain what results mean to patients and carers. The project developed an online tool, “ADappt”, to help facilitate the use of these models.

“After the diagnosis... what next? Post-diagnostic support for people with dementia and their families” was delivered by Henry Brodaty, Professor of Ageing and Mental Health, at the University of New South Wales (UNSW Sydney). He drew delegates’ attention to the fact that, despite multiple guidelines about making a diagnosis being available worldwide, guidance for the diagnostic process and post-diagnostic care and communication is sadly lacking. People diagnosed with dementia and their families and carers frequently voice dissatisfaction with the lack of communication, guidance, referral, information about management and prognosis, as well as the lack of support for living well with dementia. He introduced the COGNISANCE project, which aims to fill this gap by co-designing with people living with dementia, families and health care practitioners, and looking to implement and evaluate a package to improve post-diagnostic

care. The project, which covers five countries (Australia, UK, Netherlands, Poland and Canada), is funded by the EU Joint Programme – Neurodegenerative Disease Research (JPNDR) and funded within each participating country. The aim, once the project is completed, is to make a successful package available for local adaptation worldwide.

Charles Scerri (Malta) chaired the plenary session on “Technology and e-health”. Wijnand IJsselstein, Professor of Cognition and Affect in Human-Technology Interaction at Eindhoven University of Technology, opened the session, looking at “Warm technology and co-design with people with dementia”. He emphasised that, while some of us, as we age, will experience cognitive decline and/or dementia, this does not define who we are. “As we are focusing our scholarly and design efforts to improve the lives of people living with dementia, we are acutely aware that ageing does not equate to deterioration.” It may, however, be a part of it, he conceded. The best technology design efforts should, therefore, not focus solely on the support, substitution or amelioration of functional decline, but on better ways of affirming old age. With this in mind, there is a need to reimagine the roles of technology in old age, and to challenge the dominant but problematic rhetoric of technology as a solution for an ageing population. He highlighted the concept of “warm technology” – a framing of technology that intentionally challenges the prevalent connotation of technology as rational and efficient, yet impersonal, complicated and disconnected from an individual’s lived experience – and looked at its possible applications in dementia care.

Dag Aarsland, Head of Department of Old Age Psychiatry at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London presented a talk, “What role for ‘wearables’ in the detection of people at risk of dementia and in monitoring disease progression?”. He began by stating that measures of functional impairment in Alzheimer’s disease (AD) are made less accurate, or at least more difficult to achieve, by the fact that they rely on direct clinical observation or on caregiver recall. This is especially relevant because the presence of functional impairment is required for a diagnosis of AD, yet studies of activities of daily living have found functional impairment occurs during pre-clinical AD. Measuring cognition, behaviour and other clinically relevant domains in people diagnosed with AD in their everyday environments through the use of Remote Measurement Technologies, provides the opportunity to capture detailed data over numerous time points, which is a distinct improvement on the current means of assessment, he said. He then introduced the RADAR-AD project (Remote Assessment of Disease And Relapse – Alzheimer’s Disease). “RADAR-AD’s tailored combination of devices and smartphone applications will act as a powerful new tool in personalised medicine by offering the right treatments to the right patients for maximum effectiveness and

minimum waste”, he concluded.

Marco Blom, Scientific Director and Head of National Services at Alzheimer Nederland presented on “Identifying the needs and views of carers of people with dementia: the online platform of Alzheimer Nederland”. With the help of many family carers, and with the driving principle of delivering relevant information and functionalities for carers, Alzheimer Nederland has been able to develop a highly successful online platform.

Emma Ferguson-Coleman, a Deaf research associate within the Social Research with Deaf People (SORD) group at the University of Manchester, closed the session, giving some insight into “Navigating everyday challenges of life-story work with Deaf sign language users with dementia”. She drew attention to the fact that “Deaf British Sign Language (BSL) users consistently experience unequal access to health and social care provision, because their language and communication needs are inadequately met and their cultural identity is not recognised by the mainstream

On day three of the conference, a plenary session on “Making our societies more dementia-inclusive” was chaired by Jim Pearson (Scotland, UK) and opened with a presentation by Bernd Heise, a member of the European Working Group of People with Dementia (EWGPWD), who shared his expectations from dementia-inclusive communities, with the audience. A dementia-friendly community, he said, may be built from several single initiatives, if they can work together towards a common goal. “Such communities are founded on the consensus of all responsible persons and on greater persistence”, he stressed. He also emphasised that a truly “dementia-friendly” community requires the full inclusion of people with dementia (hence the term “dementia-inclusive”) and must promote their existing skills and interests.

“How can research lead to better prevention?” – the final plenary – chaired by Marco Blom (Netherlands) began with a presentation on “Multidomain lifestyle interventions to prevent cognitive impairment and dementia: From FINGER to World-Wide FINGERS,” given by Tiia Ngandu, Research Manager and leader of the Dementia Prevention group at the Finnish Institute for Health and Welfare in Helsinki. She emphasised the importance of finding effective preventive interventions for dementia and Alzheimer’s disease (AD), given the growing number of cases, worldwide. The multifactorial etiology of dementia and late-onset AD mean that multi-domain interventions targeting several lifestyle-related and vascular risk factors are most likely to be effective, she said. “FINGER” is a pioneering trial providing the first evidence that a multi-domain lifestyle intervention may prevent cognitive impairment. The implementation of the FINGER model in a public health context is ongoing and the FINGER model is being adapted and tested in new trials around the world, within the framework of “World-Wide FINGERS” network.

Meike Vernooij, Professor of Population Imaging at the Erasmus University Medical Center, discussed “The role of imaging in epidemiological studies: findings of the Rotterdam Scan Study.” She stated that the use of non-invasive imaging in population studies can help unravel preclinical brain changes in asymptomatic people, and as such can improve our understanding of the aetiology of Alzheimer’s disease, as well as improving risk stratification and prediction of the disease. Besides informing researchers about (preclinical) disease, this so-called “population imaging” can also help us to better understand the (normal) brain ageing process, she asserted. This has value in clinical practice in the context of assessing whether an individual has brain tissue loss that is normal for their age. New advanced image processing methods that apply artificial intelligence techniques “may lead to detection of new biomarkers that may further improve risk prediction,” she said.

Sebastian Köhler, Associate Professor at the School for Mental Health and Neuroscience at Maastricht University and Senior Researcher at the Alzheimer Centrum Limburg at Maastricht UMC+ ended the session, stressing the importance of immediate action, where dementia prevention is concerned. “Our own research shows that most people think dementia is inevitable. We need to inform the public better about what can be done to reduce the risk and create awareness,” he urged. There is consistent evidence that several lifestyle factors improve brain health later in life, he said, and that, while there is currently no sure way of predicting who will or will not develop dementia and that a healthy lifestyle is not a guarantee, it does lower the risk.

Clinical trials in Alzheimer’s disease

This Special Symposium, which was sponsored by a grant from Janssen, focused on the past, present and future of clinical trials in Alzheimer’s disease. To complement the Special Symposium, conference bags included a copy of the Clinical Trials Supplement, accompanying the October 2019 edition of our Dementia in Europe magazine. The Symposium was chaired by our Executive Director, Jean Georges.

Brian Inglis, a Scottish participant in the EPAD (European Prevention of Alzheimer’s Disease) longitudinal cohort study, opened the Special Symposium by speaking about his experiences of this clinical study. He spoke about what motivated him to participate in Alzheimer’s disease research, giving an overview of what is involved in being an EPAD participant. He then highlighted some of the personal benefits, opportunities and learnings that he gained from participating in EPAD.

The next speaker, Simon Lovestone, Professor of Translational Neuroscience at the University of Oxford, is one of the academic partners of the EPAD consortium. In his presentation, he took stock of what we have learned from unsuccessful clinical trials for

Alzheimer's disease. He emphasised three important points: firstly, we have learned that better drugs need to be developed, by diversifying the types of therapy under development and by focusing on improved targets for intervention. Secondly, we have learned that it is important to treat the right people: in the past, trials have recruited participants who are not affected by the pathology that the drug aims to treat. Clinical trials should therefore capitalise on recent advances in biomarker research, which will improve our ability to monitor the efficacy of treatment and accurately diagnose Alzheimer's disease at much earlier stages of disease development. Thirdly, we have learned that collaboration is key: drug development is a hugely costly process but by working together in public-private consortia such as EPAD and EMIF (European Medical Information Framework) we can accelerate the development of new therapies for Alzheimer's disease.

Philip Scheltens, Director of the Alzheimer Center Amsterdam at Amsterdam UMC, closed the Special Symposium with a talk on new

avenues for Alzheimer's research. He spoke about the failure of clinical trials investigating drugs such as crenezumab, solanezumab, verubecestat and lanabecestat, all of which target amyloid beta. He finished his presentation by highlighting some of the clinical investigations currently underway, identifying new targets for therapy and lifestyle interventions aimed at preventing or delaying the onset of Alzheimer's disease dementia.

The achievements of the 2nd European Joint Action on dementia

A Special Symposium was organised by the 2nd European Joint Action on dementia – “Act on Dementia”. The session began with an overview of the main priorities of the Joint Action, which include improving dementia diagnosis process and delivery; post-diagnostic support; addressing delays in detection and diagnosis in ambulatory care settings; improving crisis response services and care coordination; addressing behavioural and psychological symptoms in residential care settings; and collating evidence-based infor-

mation and recommendations on promoting, nurturing and sustaining dementia-friendly communities.

The presenters highlighted some of the strategies used to address these priority areas, such as collaborating with international experts, training GPs, nurses and nursing home staff, and developing good practice recommendations and dementia care guidelines based on literature reviews. The Joint Action pilot programmes in care settings in Bulgaria, Romania, France, Scotland, Italy and the Netherlands include education packages for professionals, as well as support for GPs and informal carers. Details of pilot projects in Bulgaria, Greece and Romania were shared. These projects adapted and tested models to address the behavioural and psychological symptoms of dementia in residential care homes.

The next Alzheimer Europe Conference (#30AEC) “Building bridges” will take place in Bucharest, Romania from 20 to 22 October 2020.

To list your event in this diary email Rachel@acnr.co.uk by 29th March 2020

FEBRUARY

MS Leadership MasterClass

Module 1: 19-21, February 2020; Module 2: 30 September – 2 October 2020; Halifax Hall, Sheffield University Campus, UK <https://multiplesclerosisacademy.org/courses/leadership>

Neurorehabilitation After Stroke

26 February, 2020; London, UK www.ucl.ac.uk/short-courses/search-courses/neurorehabilitation-after-stroke

MARCH

Neurology 2020

6 March, 2020; RCP Glasgow, UK <https://rcpsg.ac.uk/events/NEURO>
E. Hanne.Wylie@rcpsg.ac.uk

Edinburgh Sleep Medicine Course

9-13 March, 2020; Edinburgh, UK www.sleepconsultancytld.co.uk/courses/edinburgh/
E. lisa@sleepconsultancytld.co.uk

Fundamentals of Neuroradiology

11-13 March, 2020; Sheffield, UK www.sth.nhs.uk/services/a-z-of-services?id=276&page=174
E. emmafrith@nhs.net

Palliative Care MasterClass

11-12 March, 2020; Halifax Hall, Sheffield University Campus, UK <https://neurologyacademy.org/courses/palliative-care/>

Challenges to Speech and Language Intervention in Brain Injury Event

16 March, 2020; Northampton, UK – 9.30am-1.30pm plus networking lunch www.priorygroup.com/nhs/education-events-and-resources/event-timetable

MS Foundation MasterClass

Module 1: 18-20 March 2020; Module 2: 17-18, September 2020; Halifax Hall, Sheffield University Campus, UK <https://multiplesclerosisacademy.org/courses/foundation-masterclass/>

Birmingham Movement Disorders Course

18-20th March, 2020; Birmingham Conference & Events Centre, UK – www.birminghammodis.com

ILAE EEG and Seizure Semiology course

18-20th March, 2020; Cambridge, UK www.cam-pgmc.ac.uk/courses/uk-ilae-eeeg-2020
E. mc2170@medschl.cam.ac.uk

British Association of Stroke Physicians – Trainees' Teaching Weekend

21-22 March, 2020; Oxford, UK <https://fitwise.eventsair.com/basp-trainees-teaching/>
E. Events@fitwise.co.uk

Parkinson's Advanced MasterClass

Module 1: 24-25 March 2020; Module 2: 17-18 November 2020
Halifax Hall, Sheffield University Campus, UK <https://parkinsonsacademy.co/courses/advanced-masterclass-course/>

4th ILAE British Branch Epilepsy Neuroimaging Course

26-28 March, 2020; Chalfont Centre for Epilepsy, UK ow.ly/gT4U50xeMa – E. registrations@ilaebritish.org.uk

British Society for Clinical Neurophysiology – Triennial Teaching Course

30 March – 3 April, 2020; Oxford, UK <http://bscn.org.uk/event-details.aspx?Group=events&id=50>

20th Neuroradiology & Functional Neuroanatomy Course

30 March – 2 April, 2020; London, UK <https://onlinestore.ucl.ac.uk/conferences-and-events/faculty-of-brain-sciences-c07/ucl-institute-of-neurology-d07/d07-20th-neuroradiology-functional-neuroanatomy-course> – E. d.blundred@ucl.ac.uk

APRIL

AAT-AD/PD 2020

2-5 April, 2020; Vienna, Austria www.aat-adpd.kenes.com – E. isimeonov@kenes.com

ACPIN International Multidisciplinary Conference 2020 In collaboration with the Primary Care and Community Neurology Society

29 April – 1 May, 2020; ICC, Wales www.acpin.net/2020-conference

MAY

2nd International Conference on Neuro-Rehabilitation (NEURAM 2020)

27-28 May, 2020; Balaclava, Mauritius <https://zibrant.eventsair.com/neuram-2020/neuram>
E. neuram@bcdme.com – T. 0203 238 8683

JUNE

Liverpool Neurological Infections (NeuroID)

3-4 June, 2020; Liverpool, UK www.liv.ac.uk/neuroidcourse – E. bglennon@liverpool.ac.uk

MS Intermediate MasterClass

Module 1: 10-12 June 2020; Module 2: 3-4 December 2020; Halifax Hall, Sheffield University Campus, UK <https://multiplesclerosisacademy.org/courses/intermediate-masterclass>

JULY

Alzheimer's Advanced MasterClass

Module 1: 8-9 July 2020; Module 2: dates TBC (approx. 6 months later); Halifax Hall, Sheffield University Campus, UK dementiaacademy.co/courses

AUGUST

NSANZ 2020: Neuromodulation Society of Australia & New Zealand

7-9 August, 2020; Queensland, Australia <https://dcconferences.eventsair.com/nsanz2020/>
E. elodie@dcconferences.com.au

SEPTEMBER

VasCog 2020

9-12 September, 2020; Newcastle University, UK www.vas-cog.com/vascog-2020
E. vascogsoc@gmail.com

Parkinson's Foundation MasterClass

15-16 September, 2020; Halifax Hall, Sheffield University Campus, UK <https://parkinsonsacademy.co/courses/foundation-masterclass-course/>

OCTOBER

7th Global Medical Symposium for Ketogenic Dietary Therapies

6-10 October, 2020; Brighton, UK www.matthewsfriends.org/global-keto-2020
T. 01342 836571 – E. enq@matthewsfriends.org

Dementia MasterClass

8-9 October, 2020; Halifax Hall, Sheffield University Campus, UK dementiaacademy.co/courses

NOVEMBER

MS Advanced MasterClass

Module 1: 4-6 November 2020; Module 2: 20-21 May 2021; Halifax Hall, Sheffield University Campus, UK multiplesclerosisacademy.org/courses/msologists-masterclass/

MS Service Provision in the UK 2020

12-13 November, 2020; Birmingham, UK multiplesclerosisacademy.org/courses/ms-variance

Encephalitis Conference

8th December, 2020; Royal College of Physicians, London www.encephalitis.info/conference

2022

June

6th World Parkinson Congress

7-10 June, 2022; Barcelona, Spain info@worldpdcongress.org
www.worldpdcongress.org

ILAE British Branch

4th ILAE British Branch Epilepsy Neuroimaging Course

Thu 26th - Sat 28th March 2020
Chalfont Centre for Epilepsy,
Chalfont St Peter, UK

Course website & programme:

<https://ilaebritish.org.uk/events/ilae-british-branch-epilepsy-neuroimaging-course-26-28th-march-2020>

Overview:

Medical imaging is integral to the diagnosis, monitoring & treatment of modern epilepsy care and has greatly increased our understanding of this complex neurological condition. Open to all healthcare professionals & affiliates & MSc/PhD students, this 2.5-day course aims to provide both an overview & a solid foundation in state-of-the-art MRI and PET scanning in epilepsy.

On completion of the course, the participants will be able to:

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Event questions or queries – Contact us at
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Cutting Edge Science for Parkinson's Clinicians 2019

Conference details: 25-26 June 2019, Macdonald Burlington Hotel, Birmingham City Centre, UK. **Report by:** Anita Chadha-Patel on behalf of the Neurology Academy. **Conflict of interest statement:** None declared.

Cutting Edge Science for Parkinson's Clinicians is a partnership educational meeting sponsored by Bial Pharma UK Ltd, and designed and delivered by the Parkinson's Academy. The theme of this two day meeting was to 'Question everything', to review what we already know, and to think about how clinical observations and cross-team collaborations can drive us forward.

Taking a tongue in cheek approach, the Coventry & Warwickshire team reviewed how Parkinson's treatment has changed over time. Ancient texts show that Ayurvedic, Chinese and Greek practitioners clearly understood the clinical presentations of tremor, rigidity, slowness, gait disturbance, dementia and depression as a symptom complex. They often already used plant-medicines, including *mucuna pruriens*, which contains levodopa,¹ and is still used today by patients seeking 'alternative' treatments. Skipping forward, the team reviewed how leading luminaries such as Charcot used astute observations to start to define Parkinson's for the modern day. The observations of Oliver Sacks of using levodopa for post-encephalitic parkinsonism have been made famous by the book *Awakenings*, but it is less appreciated that Oliver Sacks was also one of the first neurologists to warn about high doses of levodopa and the development of dyskinesia.²

The importance of collaboration was underscored by Professor Bastiaan Bloem who noted that while the importance of the multidisciplinary team (MDT) in the management of PD is something often bandied about, it generally refers to a neurologist, together with a nurse specialist and perhaps some physical and/or occupational therapy. However, Professor Bloem argued that the definition of the MDT should be expanded to reflect the modern understanding of Parkinson's as a multi-system disease. For example, dependent on need, relevant clinicians should include a gastroenterologist, pulmonologist, neuro-ophthalmologist, dentist etc.³ In his comprehensive review of the effectiveness of physical therapies, Professor Bloem noted that the effectiveness of a number of different physical therapy approaches in PD has been established,⁴ and there is now Level II evidence for occupational therapy.⁵

Understanding Parkinson's as a multifactorial disease not only affects how it should be treated, but also provides a smorgasbord of mechanisms which can be tested for their efficacy. Dr Simon Stott reviewed the current approaches to targeting disease mechanisms in Parkinson's including immunotherapy, immunomodulation, LRRK2 inhibition,

GLP1 agonists, neurotrophic factors and cell replacement. Dr Stott advocated for a field which understands Parkinson's as a syndrome and suggested that understanding of the prodrome should help subtype the syndrome and open the door to developing tailored 'precision' medicine.⁶

Research into prodromal Parkinson's is indeed rapidly growing, as many believe this period will be the main target for disease-modifying medications. Dr Alistair Noyce reviewed the wealth of evidence now supporting the idea of constipation, REM behavioural disorder, urinary dysfunction, as well as anxiety and depression as key features of this 'pre-diagnostic' phase.⁷ Individually they do not allow a diagnosis of PD, but when considered together, they reflect the gradual development of the clinical syndrome. He described the ongoing PREDICT-HD study which uses an algorithm to identify indicators of PD risk.⁸ The study is actively recruiting, looking for healthy people aged 60–80 years, who have access to the Internet, and do not have a current diagnosis of PD.

Taking on the theme of precision medicine based on genomic subtypes, Dr Camille Carroll described research into the role of homocysteine. Epidemiological evidence has clearly linked homocysteine elevation to an increased risk of coronary artery disease, stroke, and dementia. In Parkinson's, administration of levodopa drives up homocysteine levels via the COMT pathway,⁹ and is associated with worse outcomes in terms of mood and cognition.¹⁰ Studies in Parkinson's patients have shown that gene polymorphisms are related to plasma homocysteine concentration, with one genotype having much higher plasma levels than others.¹¹ Dr Carroll discussed that while an early study showed that vitamin B supplementation, but not the COMT inhibitor entacapone, reduced homocysteine levels compared to placebo,¹² the study was not enriched for the higher-risk genotypes and was too short to be able to show any impacts on cognition or mood. She proposed that it may be time to revisit the homocysteine story and evaluate how it may play into the ideas of precision medicine in PD. For example, should patients with the higher-risk polymorphism be proactively treated with Vitamin B and perhaps the new COMT inhibitor opicapone? Controlled trials would be needed to address this question.

Dr Alan Whone opened his presentation of the pioneering Bristol GDNF study by noting that, while the study did not meet its primary endpoint,¹³ many interesting findings can be realised in the data, and it

would be wrong to view this study as a failure. This was the first trial to use the specially developed delivery system direct to the putamen. The system was shown to be safe over 80 weeks, and is now being used in two new trials; one evaluating cerebral dopamine neurotrophic factor, and one for children with brain tumours. Dr Whone also highlighted the issue of subgroups. While the differences in clinical outcome between the GDNF and placebo groups were statistically indistinguishable, there was a relatively large variation in response. Of note, nine patients in the GDNF group, but none in the placebo group improved by more than 35%, although some did not improve at all. Understanding which patients responded best will be an important step forward.

In her presentation, Professor Iracema Leroi highlighted that neuropsychiatric symptoms (dementia, psychosis, depression, anxiety, apathy and impulse control disorders etc) in Parkinson's are so common, the disease is more accurately described as a neuropsychiatric disorder.¹⁴ Psychosis and dementia frequently co-exist, and the development of one often heralds the advent of the other.¹⁵ Together, they are associated with poorer quality of life, increased morbidity and mortality, and increased caregiver burden and nursing home placement.¹⁶ Cognitive stimulation therapy (CST) is an evidence-based psychosocial intervention that involves engaging and cognitively stimulating activities and discussions based on principles of errorless learning and validation. PD-CST is an individualised form of this treatment specifically for people with parkinsonian syndromes to be delivered by their care partners at home.¹⁷

"Increasing age is the main non-modifiable risk for Parkinson's. It is also the main risk factor for frailty" said Professor Richard Walker as he started his presentation. Hospital admission data shows that patients with PD are almost twice as likely to stay in hospital for more than 3 months, and even more likely to die in hospital, than other patients.¹⁸ The main reasons for admission include pneumonia, motor decline, urinary tract infection and hip fractures. One way to assess frailty is the frailty phenotype¹⁹, where frailty is defined as a clinical syndrome in which ≥ 3 of the following five criteria are present: unintentional weight loss (10lb in past year), self-reported exhaustion, weakness (grip strength), slow walking speed and/or low physical activity. As Professor Walker observed, some of these are manageable, or even preventable, with good care.

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46 Naidex

Naidex 46 – Advertiser's Announcement: Aspiring for a Better Future of Independent Living

With 20% of the UK's population being disabled, it's time for disability to be in the spotlight – Welcome to Naidex 46! Europe's most established event dedicated to the healthcare, rehabilitation and independent living industries is back for its 46th anniversary, on the 17th & 18th March 2020 at Birmingham's NEC.

Always looking to bring you the latest solutions that allow disabled people to live more independently, this year's show will put its focus on the key topics taking the industry by storm.

You'll be able to shop from 400 world-class suppliers and try before you buy, but Naidex has always been much more than a marketplace where visitors can find the latest innovations – it is a place where people come together and learn about the industry's future.

As the epicentre of the disability and healthcare world, Naidex 46 will also boast an unparalleled speaker line-up, providing you with 300 inspirational seminars. Throughout both days, seminar theatres will be brimming with information and advice, leaving audiences uplifted and empowered.

What's more, you'll be able to join experts as they predict the trends and innovations that will turn the rehabilitation sector upside-down, courtesy of the rehabilitation panel debate.

With all this lined up, Naidex will once again become the hub of the disability world, offering all the innovations that are empowering people with a disability.

Register for your FREE ticket at www.naidex.co.uk



World Congress in Geriatric Medicine: 'Back to the Roots'

Conference details: 30 August–2 September 2019, Hunter Postgraduate Medical Institute, Newcastle, New South Wales, Australia. **Report by:** Dr Peter Fletcher, Educational Director, Parkinson's Academy. **Conflict of interest statement:** None declared.

The World Congress in Geriatric Medicine 'Back to the Roots' conference was held in August 2019 in Newcastle, New South Wales, Australia. Over 300 clinicians from Geriatric Medicine, Old Age Psychiatry, Neurology and other specialties gathered for five days of learning and networking. Participants were drawn predominantly from all over Australia but also New Zealand as well as some international attendees.

The conference welcomed 25 UK-based and 25 international speakers who together with local New South Wales faculty covered topics centering on helping older people stay as healthy as possible for as long as possible. This has never been more essential or relevant as our global population ages and experiences the problems of multiple pathologies painted on the canvas of increasing frailty.

To take a quick world view, the average lifespan in the UK is now over 80 years and those living longer are an increasing proportion of our population. Japan, meanwhile, is considered 'super-aged' with over 20% of their population over the age of 65; a proportion expected to rise to 1 in 2.5 people by 2050.

In terms of Australian data, we can see that the average male reaches around 80 years old, whilst females can expect to reach almost 85. Whilst some people query whether people want to obtain that age, the average grandparent would undoubtedly say 'yes'. However, the real



point is not that they wish to reach 80 – but that they wish to be living a healthy, quality life at 80.

On the face of it these observations are good news. However, the increasing challenge is not just the decline in health in later years but also the increase in the number of people working into old age. Hence the need to preserve, maintain and protect our health, function and well-being for as

long as possible as we age.

The UK Office for National Statistics recently published a paper examining the interplay between working and caring responsibilities, noting that 'as our population ages, there will be an increased need for informal care and so a need for older people to stay in the workforce longer.' They suggest that '2 million adults in the UK are receiving informal care,' with nearly three in five carers in England and Wales aged 50 years and over and one fifth aged 50 to 69 years, providing informal care to a value of \$59.5 billion per year. This is 'the equivalent of just over 4 million adult social care workers working every week of the year at their median weekly hours.'

The need to remain healthy for longer not only impacts our own quality of life as we age, but our ability to support ourselves and our families. It also has a wider impact on our social systems and national economies, as well as our healthcare systems. Meanwhile the proportion of the population made up of those younger, working age and for example employed as carers, is diminishing.

The conference, covered by the Channel 9 local TV news, as a whole was defined by three characteristics. Firstly, it covered a phenomenal range of topics within a single programme, giving the busy clinician an enormous amount of continuing professional development in a single conference. With the essential theme of 'healthy for longer' in mind, topics included specific conditions such as stroke diagnosis and management, dementia, frailty and sarcopenia while there was a whole day on Parkinson's disease and related disorders. Medical challenges such as falls, continence problems and polypharmacy were also covered as were de-prescribing and managing the older patient undergoing surgery.

Secondly, each contribution was crafted to provide the latest evidence where available and the very best consensus thinking where it was not, both enhanced and in turn validated by the extensive question and answer sessions that followed each contribution. Comprehensive analysis of practical patient management sat alongside reviews of the most recent evidence-based medicine including detailed presentations around how to deliver high quality community geriatrics, and the importance of the comprehensive geriatric assessment.

Finally, it had immense face validity to the front-line clinician in geriatric medicine (and other specialties too) and was of enormous hands-on practical value to those managing our older patients. This is true at the bedside, but the best news is that the same principles apply in the clinic, day hospital and community. With 82% of attendees coming from geriatric medicine and 73% of these already specialists, participants were left ideally placed to put into practice much of the information shared on the latest in evidence-based care and optimal service delivery.

Dr Chandrasekhara Padmakumar, Conference Lead and Consultant Geriatrician & Clinical Leader Aged Care at John Hunter Hospital in Newcastle, NSW, Australia, said: 'The knowledge that will be gained will definitely improve and upskill the staff working... that's how we're hoping that this [conference] will translate into patient care.'

Clinicians attending this conference strive every day to keep our older patients fit and healthy and living well within their own homes, families and wider communities. This conference has done much to help participants achieve those goals.

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Royal College of Psychiatrists – Faculty of Neuropsychiatry Annual Conference

Conference details: 19-20 September 2019, Royal College of Psychiatrists, London, UK. **Report by:** Dr George El-Nimr, Consultant Neuropsychiatrist and Academic Secretary to the Faculty. **Conflict of interest statement:** None declared.

Attended by over 250 colleagues, a significant number of delegates had travelled from as far as Australia, Canada, Iran, Israel, Japan, Malta and Sweden. There was a mixture of Consultant Psychiatrists, Core/Advanced Trainees, SAS, Student Associates as well as a number of non-College members.

As always, our 2019 conference covered a number of topical clinical, research and medico-legal angles, relevant to all of those working in the field of Neuropsychiatry. Delegates were informed (and at times entertained!) by a number of carefully selected, distinguished speakers in a range of keynote presentations and seminars.

The conference opened with a succinct presentation from Prof Wendy Burn, College President that summarised recent developments in relation to the Neuroscience project and how this will benefit training, professional development and clinical practice.

Conference attendees heard about alternative, less orthodox approaches in studying memory and its disorders. Prof Johnstone delivered an excellent presentation on Alzheimer's disease and the food-gut-brain axis. The growing evidence that identifies the gut microbiota as key in the interaction between specific nutrients and brain function was highlighted, alongside the potential for considering nutritional approaches to address challenging behaviour.

In a talk entitled 'Injured mind and intact brain', Prof Kopelman of King's College then presented an argument for viewing each case of 'functional cognitive disorder' as a single-case experiment in terms of assessment and management. Following on from this, a session dedicated to the risk of developing dementia in the context of various neurological conditions and another on the Neuropsychiatry of stroke were delivered. Dr Agrawal presented data accumulated over the last few decades that points to progressive neurocognitive and neurological decline with age and repetitive injuries. The increased risk of dementia with significant traumatic brain injuries was highlighted. Similarly, the wide range of behavioural and cognitive disturbances associated with movement disorders were discussed by Prof Cavanna; being potentially the most disabling aspect of the illness.

Dementia in the context of cerebro-vascular disorders was then discussed by Dr Jeremy Isaacs. Dementia prevalence and stroke incidence are both falling in high-income countries, but the prevalence of vascular risk factors is increasing, which might reverse this trend. While stroke is a common disease and post-stroke dementia is a common complica-

tion, most strokes are due to large vessel disease, whereas the majority of vascular cognitive impairment (VCI) is due to small vessel disease, which often co-exists with neurodegenerative pathologies, such as Alzheimer's disease.

On a related theme, Prof Anthony David talked about functional stroke mimic. Acute stroke-like presentations are relatively common and have become more noticeable with the advent of hyper-acute stroke services in major centres in the UK. The lack of a clear clinical pathway for functional stroke mimics was particularly discussed. This was followed by a talk on Neuropsychiatry of stroke by Dr Dilley which was particularly relevant to clinical practice of mental health professionals. A particularly welcome update on acute stroke and its management was delivered by Dr Pereira.

Advances in Neuropsychiatric genetics were discussed in detail. Prof Sir M Owen, Director of the MRC Centre for Neuropsychiatric Genetics of Cardiff University reviewed recent advances in schizophrenia and related disorders. He also outlined their likely impact on psychiatric research and practice. Prof J Williams CBE then talked about the Neuropsychiatric genetics of Alzheimer's disease. Genomic analyses further support the contribution of immunity/inflammation and specifically highlight the role of microglia, hub genes and biological networks. Current analytics have enabled the capture of between 30 - 50% of heritability for common genetic variation in Alzheimer's disease.

Our humanities session addressed the role of art in a Neuropsychiatry setting. A presentation entitled 'Personal experience of encephalopathy through art' was delivered by Andrew Hewkin. An equally inspiring talk was presented by Alan Dyer, artist and psycholo-



gist, which summarised his personal experience of art, perception and neuroaesthetics. The talk looked at relationships between order and disorder in art and aesthetic perception.

How Neuropsychiatric patients are – and should be – managed in a general psychiatry setting was the subject of a lively debate, that triggered reflection and ideas sharing on optimal service models, as well as the management of individual patients.

Other interactive sessions included seminars on topics such as what parasomnias tell us about the brain, seizure semiology, Wilson's disease and the use of psychotropic medication in Huntington's disease. A popular seminar on Neuropsychiatry and capacity assessment was delivered jointly by a consultant Neuropsychiatrist and a barrister who emphasised the fact that assessment of capacity is pivotal to clinical practice in Neuropsychiatry. Likewise, an update on the role of expert witnesses in Neuropsychiatry was the subject of an equally popular seminar session.

In a dedicated session for trainees, our future neuropsychiatrists, high quality projects were presented and distinguished ones were presented with awards by Prof Joyce, our Faculty chair at the conclusion of the conference.

As always, the programme contents were supplemented by poster presentations, and delegates were invited to browse these at leisure.

Planning for our next AGM conference, also to be held at our Royal College in London (17 and 18 September 2020), is now underway, and a number of internationally renowned speakers are already lined up for the conference!



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